

SUCYIVORShip Conference







6-7 February 2015 Adelaide, South Australia

Proceedings of the Second Flinders Survivorship Conference

www.survivorship2015.org



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Convenor's Welcome



I am delighted to welcome you to the second Flinders Survivorship Conference. After the success of the inaugural Survivorship Conference in 2013, which brought together a diverse group of clinicians, researchers, policy makers and consumers from Australia and beyond we are coming together again to learn, to be challenged and to make a lasting impact.

The theme of the conference "Life after Cancer – from Recovery to Resilience" serves as a broad canvas on which we can explore a range of themes – from what it means to be thriving to what models of care really work. Once again we come together from multitude of perspectives, where all of us have something to offer and something to share. We hope to build on the deliberations from 2013 to

focus on some of the fundamental issues for survivors today.

Through the conference we want to achieve the lasting progress in the care of those affected by cancer and we will do so by showcasing the latest developments in care and research related to the field of cancer survivorship, by stimulating the debate on the most challenging topics in this area and by creating the environment where we can all connect and share our stories. Many of you have shared your personal commitment to progress at the time of registration and these commitments capture in just a few words what this conference is all about – dedication to making a positive change.

I hope that you will learn and be inspired; that you will connect with old friends and make many new ones and that you will find some time to enjoy the beauty of our wonderful city and its surrounds.

With best wishes,

Professor Bogda Koczwara Conference Convenor

Committees

Thank you to all the individuals who have made this conference possible, including:

Conference Convenor

Prof Bogda Koczwara Flinders Centre for Innovation in Cancer, Flinders University, SA

Scientific Program Advisory Committee

Prof Bogda Koczwara Flinders Centre for Innovation in Cancer, Flinders University, SA

Dr Daniel Byrne Chandlers Hill Surgery, SA

Dr Haryana Dhillon University of Sydney, NSW

Prof Afaf GirgisUniversity of New South Wales

Assoc Prof Michael Jefford Peter MacCallum Cancer Centre, VIC

Ms Julie Marker Cancer Voices South Australia

Ms Annie Miller Cancer Council New South Wales

Ms Danielle Tindle Queensland University of Technology

Local Organising Committee

Prof Ross McKinnon Flinders Centre for Innovation in Cancer, Flinders University,

Adelaide (Chairperson)

Dr Sinoula Apostolou Flinders Centre for Innovation in Cancer, Flinders University,

Adelaide

Ms Maxine Pollard FCIC Communication Manager,

Flinders Medical Centre Foundation, SA

Ashleigh Moore Oration 2015



The Oration was established to recognise the significant contribution of Ashleigh Moore to the field of cancer survivorship in South Australia and beyond. To commemorate Ashleigh's lasting contribution to the care of those affected by cancer, the Flinders Centre for Innovation in Cancer established the annual Ashleigh Moore Oration to recognise an individual or organisation in Australia who has made an outstanding contribution to the care of cancer survivors through contribution to clinical practice, research, policy, and/or advocacy affecting cancer survivors.

Congratulations to Sally Crossing, who will be presenting the inaugural Ashleigh Moore Oration at the 2015 conference.



Sally Crossing AM

Cancer Voices, NSW

Sally is living well with metastatic breast cancer, having been first diagnosed with early breast cancer in 1995. She founded and chaired the Breast Cancer Action Group from 1997, and Cancer Voices - the independent, generic voice of people affected by cancer from 2000. Sally was made a Member of the Order of Australia (AM) for her work in cancer consumer advocacy in 2005, and received an Honorary Doctorate (University of Sydney) in 2014 "in recognition of extraordinary leadership and contributions to supporting those with cancer from diagnosis, through treatment, care, support and survivorship in both advocacy and research". Sally is Convenor of Cancer Voices Australia which also facilitates the Australian Cancer Consumer Network — bringing together a bigger (30 consumer groups) voice for Australians affected by cancer.

Invited Speakers



Dr Daniel Byrne

SA&NT Faculty Royal Australian College of General Practitioners, Adelaide

Dr Danny Byrne is a general practitioner at Chandlers Hill Surgery, Adelaide 24km south of the city in an outer metro practice. He owns the practice with 6 other general practitioners. Another 12 associate GPs work there. The practice currently has 7 Doctor's consulting rooms running. There are 3 registered nurses, physiotherapy, psychology, pathology, podiatry and specialist immunologist all on site. Dr Byrne is also a Medical Educator with local Registered Training Provider Sturt Fleurieu. He has been a Medical Educator for over 10 years. He also works closely with Medicare Locals providing GP relevant input into their programs. His special area of interest is eHealth and improving linkages between the hospital and community sectors



Mr David Chapman

CanSpeak Australia, South Australian Representative

Non Hodgkins Lymphoma (diag. 2004)
Former Deputy Chairman and Treasurer of Cancer Voices SA
Current SA representative of CanSpeak Australia
Current Member of COSA Survivorship Working Party



Dr Haryana Dhillon

University of Sydney, NSW

Dr Haryana Dhillon, Research Fellow in Cancer Survivorship at the Centre for Medical Psychology and Evidence-based Decision-making (CeMPED) University of Sydney. CeMPED Deputy Director, Central Clinical School. President of the Australian Psycho-Oncology Society (OZPOS), a member of the Clinical Oncological Society of Australia (COSA) Executive Committee and Council. Dr Dhillon' career has had two distinct phases. She worked in a research support capacity for ten years at the NHMRC Clinical Centre where she contributed to investigator-initiated clinical trials research and the development of several of Australasia's Cancer Cooperative Trials Groups. In 2005, she commenced a PhD in informed consent for colonoscopy, awarded in 2010. During this time Dr Dhillon started collaborations with A/Prof, Janette Vardy, with whom she established a Cancer Survivorship Research Group. The group is supported on peer-reviewed funding; allowing them to run studies in cancer and cognition, physical activity in cancer populations, sleep disturbance and symptom control. Haryana also maintains active research interests in health literacy, communication in the cancer setting and patient education.



Prof Elizabeth Eakin

University of Queensland, Brisbane

Professor Elizabeth Eakin is Director of the Cancer Prevention Research Centre, within the School of Population Health, The University of Queensland. She is a behavioural scientist with extensive experience in the conduct of randomized controlled trials of health behaviour interventions, including those targeting cancer survivors, and in the translation of these into population health practice. She is the lead investigator on a recently funded NHMRC Partnership Project involving the Cancer Councils Victoria, NSW, SA and WA in the implementation and evaluation of a lifestyle intervention for cancer survivors that will be delivered by Cancer Council nurses via the 13 11 20 Information and Support Service.



Prof Afaf Girgis

Ingham Institute for Applied Medical Research; University of New South Wales, Sydney

Professor Girgis is Director of the Psycho-oncology Research Group at the Ingham Institute for Applied Medical Research & UNSW in Sydney, Australia. She has worked for more than 24 years as a Behavioural Scientist in cancer control and psycho-oncology. Her national and international standing in behavioural science and psycho-oncology was acknowledged in 2012 with the award of the Clinical Oncology Society of Australia (COSA) Inaugural Psycho-oncology Award. Afaf has a strong commitment to translating research into clinical practice; and a

demonstrated track record of effective engagement with service providers, endusers of research and the community, to ensure the relevance and acceptability of interventions aimed at improving cancer care and outcomes. Afaf has more than 230 publications, over 5500 citations of her research and more than \$38 Million in collaborative research funding; and has conducted complex multicentre randomised controlled trials of psycho-oncology interventions.



Assoc Prof Michael Jefford

Peter MacCallum Cancer Centre, Melbourne

Associate Professor Michael Jefford is Deputy Head of the Department of Medical Oncology at Peter MacCallum Cancer Centre (Peter Mac), Senior Clinical Consultant at Cancer Council Victoria and a Principal Fellow at the University of Melbourne. He completed medical oncology training (FRACP) in 1999 and holds a PhD (2002) and Graduate Certificate in University Teaching (2013) from the University of Melbourne and Masters degrees in Health Services Management (2003) and in Public Health (2006) from Monash University. Michael is a practicing medical oncologist. He is also Director of the Australian Cancer Survivorship Centre, a Richard Pratt legacy, based at Peter Mac. He has led research and contributed to program development, service delivery and to the international literature regarding cancer survivorship. He has been awarded over \$10m in grant funding as a chief / principal investigator, has published over 100 peer-reviewed manuscripts and book chapters and has presented work at numerous national and international meetings.



Ms Gabrielle Kelly

SAHMRI Centre for Wellbeing and Resilience, Adelaide

Gabrielle Kelly is the SAHMRI Wellbeing and Resilience Centre's inaugural Director. Film-maker, digital media executive, social entrepreneur and strategist, she has been working on human behaviour and systems change in a range of settings. Previously, she ran the ground-breaking Adelaide Thinkers in Residence program, leading significant implementation of change in city design, advanced manufacturing, early childhood education, and positive psychology. As Senior Vice President of the Health Accord in New York, a digital start up, she developed a business to deliver health and wellbeing products to self-directed health consumers in 1999/2000. This "capacity for self-direction" has gone global and viral with the arrival of the internet. She commissioned and led the Professor Martin Seligman residency in South Australia with a range of high profile partners to explore the value of positive psychology in building mental wellbeing and resilience and reducing mental illness. South Australia has now accepted Professor Seligman's challenge to become the 'State of Wellbeing', measuring, building, and embedding positive psychology, and wellbeing and resilience science in the community at large. The vision: to use Professor Seligman's dashboard of wellbeing - Positive Emotion, Engagement, Relationships, Meaning and Accomplishment (PERMA) – as a public health message for all citizens across all age cohorts. Like 'Slip Slop Slap', PERMA+ will become the clarion call for a mentally healthy society in Australia.



Prof Bogda Koczwara

Flinders Centre for Innovation in Cancer, Flinders University, Adelaide

Professor Bogda Koczwara is a medical oncologist and the Director of Medical Oncology for the Southern Adelaide Health Service. Her clinical interests revolve around management of breast cancer, in particular in young women, survivorship care, psychooncology and supportive care and she has a particular interest in strengthening the interface between specialist and primary care for cancer patients, especially in rural Australia.



Ms Annie Miller

Cancer Council New South Wales, Sydney

Annie Miller is the Manager of Practical Support at Cancer Council NSW. This extensive portfolio includes; Survivorship team, Pro Bono Legal and Financial program, Cancer Council Information Centres, Transport and Home Help and Financial Assistance. With a background in business, management, life coaching and stakeholder engagement across the not-for-profit and corporate sectors Annie is passionate about translating research for strategic, practical and emotional support services development for effective sustainable delivery across metro and rural areas. Annie has a depth of experience in innovative program and project development, community education, working hands on with people affected by cancer and is passionate about collaborative effective work with allied organisations and colleagues. She is a Partner Investigator on Research grants, a member of the COSA survivorship working group and the developer of the successful Living Well After Cancer program. In addition to this she has experienced 6 1/2 years of lived experience as a cancer carer.



Dr Michael Osborn

Royal Adelaide Hospital, Adelaide

Michael Osborn is a haematologist and paediatric, adolescent and young adult oncologist. As well as working at the Women's and Children's Hospital Department of Haematology and Oncology, he has also lead the South Australian / Northern Territory Youth Cancer Service since 2011. This group works across both the paediatric and adult sectors, with the aim of optimising the clinical and psychosocial management of 15 - 25 year olds with cancer across SA and NT. He is part of the national Youth Cancer Services Research Advisory Group and Dataset Advisory Group, and contributed to the development of the Clinical Oncology Society of Australia's "Psychosocial Guidelines for the Management of Young People with Cancer." He also coordinated the development of a standardized Survivorship Psychosocial Assessment Tool and Care Plan for teenagers and young adults who have completed cancer treatment; this has been piloted in a number of Australian states. His main clinical interest is leukaemia in children, teenagers and young adults, as well as exercise and nutrition during and after cancer treatment.



Mr Luke Ryan

Writer, comedian and two-time cancer survivor, Melbourne

Luke Ryan is a Melbourne-based writer, comedian and two-time cancer survivor. His first book, A Funny Thing Happened on the Way to Chemo, is a comic memoir about growing up and getting cancer that grew out of his critically acclaimed 2009 Melbourne Comedy Festival show, Luke's Got Cancer. Inspiring, engaging and with a unique comic edge, Luke brings years of stand-up, storytelling and speechmaking experience to bear on topics as diverse as handling adversity, bullying, discovering perspective, getting the most out of life and finding one's vocational direction.



Assoc Prof Sabe Sabesan

James Cook University and Townsville Cancer Centre, Townsville Hospital

A/Prof Sabe Sabesan, BMBS(Flinders), FRACP is the director of the department of medical oncology at the Townsville Cancer Centre, Townsville Hospital, Queensland and the Clinical Dean of the Townsville Clinical School, the school of medicine and dentistry at the James Cook University, Townsville ,Australia. He pioneered a large teleoncology network and a novel remote chemotherapy supervision model in north Queensland. He has been a member of the Queensland state-wide rural and remote clinical network, QH Telehealth governance committee and RACP Telehealth working group. Currently, he is the chair of the regional and rural group of the Clinical Oncology Society of Australia.



Prof Graeme Suthers

SA Pathology, Adelaide

Graeme Suthers trained in clinical and laboratory genetics in Sydney, Adelaide, and Oxford. He is currently Head of the South Australian Clinical Genetics Service, and is responsible for familial cancer services provided in South Australia. He is Chair of the Genetics Advisory Committee of the RCPA. He is a member of the Medical Services Advisory Committee of the Australian Department of Health & Ageing, and of the Australian Government's Genetics Working Party.



Ms Danielle Tindle

Institute of Health and Biomedical Innovation, Queensland University of Technology, Brisbane

Danielle approaches the topic of cancer survivorship from an interdisciplinary perspective, given her academic and professional background in the field and also her personal experience as a long-term cancer survivor. Her particular interests include the phenomenon of cancer survivorship as experienced by adolescents and young adults (AYA) around the world, and how meaning and self-concept develop following a cancer diagnosis. Danielle recently completed PhD research exploring the cancer survivorship experiences of young adults in Australia, England and the United States. Her cross-cultural study was supported by a three year PhD scholarship awarded by the Leukaemia Foundation. In both professional and consumer advocacy roles, Danielle is involved with a variety of national and international organisations and projects. She is also an advisory committee member of CanSpeak Queensland, the peak consumer advocacy organisation representing Queenslanders whose lives have been affected by cancer. Danielle holds postgraduate qualifications in Teenage and Young Adult Cancer Care (Coventry University, UK), a Bachelor of Arts majoring in Philosophy (University of Queensland) and Masters of International Studies (University of Sydney).



Dr Adrienne Walker

BreastScreen SA, Adelaide

I started my medical career in General Practice, working for 20 years, mostly in Australia but with a few years in the UK. Over that time I developed a special interest in Palliative Care. I developed APML (Acute Pro-Myelocytic Leukaemia) in 2004. One day I was consulting, and the next day I was having a bone marrow biopsy. I resigned from my position as Senior Partner that day. After treatment I had a year off work on the advice of my specialist, and then returned to working part-time at BreastScreen SA where I have been ever since. I am retiring at Christmas. Ten years ago I did not think I would see another. My plan is to continue making the most of each and every day.



Ms Kathryn Whitfield

Victorian Department of Health, Melbourne

Kathryn currently works within the Department of Health Victoria as Acting Manager Cancer Strategy and Development, following almost 5 years in her substantive role as Manager Cancer Reform which encompasses the Integrated Cancer Services and Quality programs. Prior to this she worked as; Manager of the Cancer Control Program within Queensland Health, a lecturer/researcher at LaTrobe University/UoM, and various roles in the health care sector.



Ms Leonie Young

Wesley Hospital Kim Walters Choices Program, Brisbane

Leonie was diagnosed with breast cancer in 1987. Since her diagnosis she has been involved with many aspects of breast cancer advocacy and support with both national and international cancer organisations. Her involvement now also includes organisations concerned with other cancers. Leonie is a member of the consumer advisory groups of the Australia & New Zealand Breast Cancer Trials Group (Chair) and the National Breast Cancer Foundation. She is also Chair of the Cancer Trials Consumer Network, a network for consumers who specifically work with cancer clinical trials groups and of CanSpeak Queensland which aims to provide a voice for people affected by cancer in Queensland. Since her diagnosis Leonie has been a breast cancer support volunteer with the Cancer Council Queensland. Leonie is the Peer Support Coordinator for the Wesley Hospital Kim Walters Choices Program in Brisbane which offers support and information to people affected by cancer.



Mr Matthew Zachary

Stupid Cancer, USA

Diagnosed with brain cancer at 21, concert pianist and ad-agency veteran Matthew Zachary is the Founder of Stupid Cancer, the nation's dominant youth and young adult cancer advocacy non-profit. As CEO, he built the team that launched a social movement by disrupting and innovating the non-profit model and uniting several industries to embrace the cause of young adult cancer survivorship. Matthew has a BA in Music, Computer Science and Sociology from Binghamton University and lives in Brooklyn with his wife and twins.

Session Chairs

Each of the conference sessions is hosted by session chairs who bring to the topic a survivor and clinical or research perspective. We thank each individual for volunteering their time to take part in this important meeting.



Dr Daniel Byrne

SA&NT Faculty Royal Australian College of General Practitioners, Adelaide

Please refer to the Invited Speakers section for a full biography.



Dr Haryana Dhillon
University of Sydney, NSW
Please refer to the Invited Speakers section for a full biography.



Prof Afaf Girgis
Ingham Institute for Applied Medical Research; University of New South Wales, Sydney
Please refer to the Invited Speakers section for a full biography.



Assoc Prof Michael Jefford

Peter MacCallum Cancer Centre, Melbourne

Please refer to the Invited Speakers section for a full biography.



Prof Bogda Koczwara

Flinders Centre for Innovation in Cancer, Flinders University, Adelaide

Please refer to the Invited Speakers section for a full biography.



Ms Julie Marker

Cancer Voices SA

Cancer Survivorship wasn't a term being used when I was first diagnosed with colon cancer in 2001, or after liver secondaries were found in 2005 and 2006. After joining Cancer Voices SA in 2007, I now try to 'give back', using this experience to advocate, share information and help others. Through all my treatment I searched for information to help me understand, make decisions and cope better with what we were going through. I discovered meditation helped me with the emotional roller-coaster of relapses, fear and uncertainty. Cycling helped too with physical and mental toughness, proving we're a lot stronger than we might think we are!



Ms Annie Miller

Cancer Council New South Wales, Sydney

Please refer to the Invited Speakers section for a full biography.



Prof Ross McKinnon

Director, Flinders Centre for Innovation in Cancer; Professor in Cancer Research, Flinders University

Professor Ross McKinnon is the Foundation Director of the Flinders Centre for Innovation in Cancer and Professor in Cancer Research at Flinders University. He also holds Professorial appointments in the Faculty of Pharmacy and Pharmaceutical Sciences at Monash University and the School of Pharmacy and Medical Sciences at the University of South Australia. Professor McKinnon was previously the National Facilitator for the Translating Health Discovery into Clinical Applications Super Science Project and the Inaugural Director of the Sansom Institute at the University of South Australia. A pharmacist by training, Professor McKinnon has a broad research agenda relating to the discovery, development and optimal use of medicines in cancer and related conditions and is an author of more than 350 published outputs. His research interests include a strong focus on the increased clinical uptake of pharmacogenomics and personalised medicine. He holds a number of patents with collaborators at UniSA related to chemoprevention for skin cancer and the identification of novel anti-inflammatory plant extracts and purified compounds based on indigenous knowledge. Professor McKinnon holds a number of prominent positions nationally and internationally including Vice-President of the International Pharmaceutical Federation and Chair of the 2014 Pharmaceutical Sciences World Congress to be held in Melbourne. He was named as a member of the National Health and Medical Research Council Academy in 2010 and was awarded the Australasian Pharmaceutical Science Association's highest honour, the APSA Medal in 2011.



Ms Meg Rynderman

Volunteer, Australian Cancer Survivorship Centre; Volunteer, Cancer Council Victoria's Cancer Connect program

Meg Rynderman is a survivor of recurrent Hodgkin disease & hormone positive Breast Cancer. Treatment for her disease has included radiotherapy, high dose chemotherapy, stem cell transplant, bi-lateral mastectomy & reconstruction. Meg volunteers her time at the Australian Cancer Survivorship Centre and also

volunteers for Cancer Council Victoria's Cancer Connect program. Meg's 20-year cancer journey has instilled in her a passion that other cancer survivors should be offered more appropriate support and follow-up care than she experienced in her early years and that cancer should no longer be seen as a one-off incident, but rather a whole-of-life health issue. Meg is a Governor of Bialik College in Hawthorn and has a background in family business.



Mr Michael Sexton

ABC TV, Adelaide

Michael Sexton has been a journalist for more than 30 years having worked for Channel 9, the BBC and the ABC. For 15 years he was the South Australian correspondent for the 730 Report. He has made several documentaries and is the author of five books.



Ms Danielle Tindle

PhD Candidate at the Institute of Health and Biomedical Innovation, Queensland University of Technology (QUT)

Please refer to the Invited Speakers section for a full biography.



Dr Agnes Vitry

Senior Research Fellow at the University of South Australia

Agnes is a drug information pharmacist who has been working as a Senior Research Fellow at the University of South Australia for the last 10 years. She has a strong research interest in the quality use of medicines, quality of medicine information for health professionals and consumers, medicines policy and regulation. In 2003, Agnes was diagnosed with breast cancer. It was the start of a survivorship journey where her professional interests and her health activist involvement helped her to understand the new challenges of living with cancer. In 2009, she began to collaborate with Cancer Voices SA to encourage and support the recognition of the experiences and views of cancer patients, their carers and supporters and to promote their participation in all aspects of cancer health care and research.



Dr Kate Webber

Medical Oncologist; Research Fellow at the University of New South Wales

Dr Kate Webber is a medical oncologist and the inaugural Survivorship Research Fellow of the NSW Cancer Survivors Centre at UNSW. Cancer survivorship is the main focus of her clinical and research work, with a particular focus on residual and late toxicity of cancer treatment and its impact on quality of life. At the NSW Cancer Survivors Centre Dr Webber assesses the needs of cancer survivors and facilitates development of individualized Cancer Survivorship Care Plans. A prospective cohort of cancer survivors recruited through this clinic will be followed long-term to examine predictors of well-being and adverse outcomes after cancer therapy.

Program

Friday 6th February 2015

7.30am	Registration desk open	Riverbank Foyer	
8.45 – 9.00am	Official Welcome Riverbank Rooms 7 & a Prof Ross McKinnon, Flinders Centre for Innovation in Cancer Nick Xenophon, Independent Senator for South Australia		
9.00 -10.00am	Plenary 1 – Where have we come from? Where are w	ve going? Riverbank Rooms 7 & 8	
	Session Chairs: Prof Ross McKinnon, Flinders Centre fo Dr Agnes Vitry, University of South Australia	r Innovation in Cancer	
	Two years later – what has changed? Prof Bogda Koczwara, Flinders Centre for Innovation Flinders University, SA	in Cancer,	
	Ashleigh Moore Oration: Surviving is not enough: Ms Sally Crossing AM, Cancer Voices, NSW		
10.00 - 10.30am	Morning Tea	Riverbank Foyer	
10.30 - 12.30pm	Plenary 2 – The spectrum of illness and wellness	Riverbank Rooms 7 & 8	
	Session Chairs: Ms Danielle Tindle, Queensland University of Technology Dr Daniel Byrne, Chandlers Hill Surgery, SA		
	Life beyond a cancer diagnosis: Mere survival or meaningful survivorship? Ms Leonie Young, Australia & New Zealand Breast Cancer Trials Group, QLD		
	Dealing with the Sword of Damocles: A/Prof Michael Jefford, Peter MacCallum Cancer Cen	tre, VIC	
	Building resilience in the state of wellbeing: measurement, interventions, transmission, evidence and community in a life course approach: Ms Gabrielle Kelly, Wellbeing and Resilience Centre, SA		
	<u>Proffered Papers</u>		
	Developing cancer survivor stories, personal narratives by a cancer consumer Mrs Meg Rynderman, Peter MacCallum Cancer Centr		

Conceptualisation of post-treatment survivorship: experiences from different cultural groups

Ms Linda Nolte, Peter MacCallum Cancer Centre, VIC

Resilience following breast cancer treatment - findings from a prospective study **Dr Barbara Bennett, NSW Cancer Survivors Centre**

"More than just telling my story" when cancer survivors become teachers Ms Julie Marker, Cancer Voices South Australia

Panel discussion

12.30 - 1.30pm

Lunch and poster viewingPoster session proudly sponsored by



Riverbank Foyer

1.30 - 3.30pm

Plenary 3 – Challenges and solutions

Riverbank Rooms 7 & 8

Session Chairs: Ms Julie Marker, Cancer Voices South Australia Dr Kate Webber, NSW Cancer Survivors Centre

Proffered Papers

ICF core set development for lymphoedema in Australia
Ms Shannon Vanderstelt, Flinders University, SA

Addressing the gap- meeting the long term survivorship and rehabilitation needs of women living with secondary breast cancer

Ms Danielle Spence, Breast Cancer Network Australia, VIC

What is the effect of nutrition interventions on long term cardiovascular and metabolic parameters in cancer survivors and patients?

Prof Bogda Koczwara, Flinders Centre for Innovation in Cancer, Flinders University, SA

What Is Important To Research: The Cancer Survivors' Voice A/Prof Sharon Lawn, Flinders Centre for Clinical Innovation, SA

Improving bone health of cancer survivors – a complex implementation problem Prof Bogda Koczwara, Flinders Centre for Innovation in Cancer, Flinders University, SA

A Nurse-Led Lifestyle Intervention for Endometrial Cancer Survivors Ms Elisha McLaren, The University of Sydney, NSW

Finding My Way: An interim analysis of predictors of adherence to an internet self-help program for cancer-related distress

Emma Kemp, Flinders University, SA

What are cancer survivors attending the Sydney Survivorship Clinic like and what do they need?:

A/Prof Janette Vardy, University of Sydney, NSW

Complementary therapies – exploring preferences to inform a model of care Ms Amanda Piper, Australian Cancer Survivorship Centre, Peter MacCallum Cancer Centre, VIC

3.30 - 4.00pm	Afternoon Tea	Riverbank Foyer	
4.00 - 5.30pm	Plenary 4 – Are late effects inevitable?	Riverbank Rooms 7 & 8	
	Session Chairs: A/Prof Michael Jefford, Peter MacCallum Cancer Centre, VIC Mrs Meg Rynderman, Peter MacCallum Cancer Centre, VIC		
	Late effects - what can we learn from survivors of chi Dr Michael Osborn, Royal Adelaide Hospital, SA	ildhood cancer?	
	Supporting Healthy Lifestyles among Cancer Survivor Population-based and Clinical Approaches Prof Elizabeth Eakin, The University of Queensland	rs – The Intersection of	
	Genes, survival, and survivorship Prof Graeme Suthers, Sonic Healthcare, SA		
	<u>Proffered papers</u>		
	Genetic associations and trajectories of fatigue and a after breast cancer treatment: Results from a prospe Dr Kate Webber, NSW Cancer Survivors Centre		
	Metabolic complications in childhood cancer survivor A/Prof Richard Cohn, Sydney Children's Hospital, N		
	Cutting Through the Fog: Nurses' Perceptions of Cand Cognitive Impairment Jacqueline Kemmis-Riggs, University of Sydney, NSV		
	Panel discussion		
5.30 - 7.30pm	Welcome reception BBQ Dinner at the Adelaide Convention Centre	Riverbank Promenade	

Saturday 7th February 2015

7.30am	Registration desk open (until 15:30)	Riverbank Foyer	
7.40 - 8.15am	Breakfast Session	Riverbank Rooms 7 & 8	
	Survivorship in the Information Age – using advances in technology to provide high quality cancer care Ms Deidre Besuijen, Hunter New England Health LHD, NSW		
8.30 - 9.00am	Book Reading	Riverbank Rooms 7 & 8	
	Session Chair: Prof Bogda Koczwara, Flinders Cen Flinders University, SA	ntre for Innovation in Cancer,	
	A Funny Thing Happened on the Way to Chemo Luke Ryan, Writer, comedian and two-time cand	cer survivor, Melbourne	
9.00 - 10.30am	Plenary 5 - Models of care I - from self care to pr	rimary and specialist care Riverbank Rooms 7 & 8	
	Session Chair: Dr Haryana Dhillon, University of S	Sydney, NSW	
	I just need a referral Dr Daniel Byrne, SA&NT Faculty Royal Australian Practitioners, Adelaide	n College of General	
	Empowering survivors to achieve their own goals self-management Prof Afaf Girgis, University of New South Wales	of care: The role of	
	<u>Proffered Papers</u>		
	Shared care of cancer patients in primary and spe a principle based implementation process Prof Bogda Koczwara, Flinders Centre for Innova University, SA		
	The ProCare Trial - an RCT of shared care for follo cancer Prof Jon Emery, University of Melbourne, VIC	ow-up of men with prostate	
	Poster discussion lead by A/Prof Michael Jefford, Peter MacCallum Cancel	r Centre, VIC	
	Posters for discussion		
	Survivorship challenges for Australian women wit	th breast cancer	

Ms Michelle Marven, Breast Cancer Network Australia, VIC

Fit to Thrive: A Specialised Exercise Program to support patients with a haematological malignancy

Mrs Maryanne Skarparis, Leukaemia Foundation of Queensland

Research on cancer survivorship in Australia: current status, gaps and needs **Dr Agnes Vitry, University of South Australia**

Defining the role of occupational therapy in cancer survivorship A/Prof Lynette Mackenzie, University of Sydney, NSW

Strengthening survivor's roles in cancer trials advisory groups

Joint Community Advisory Group (JCAG), Primary Care Collaborative Cancer

Clinical Trials Group (PC4), WAPsycho-Oncology Clinical Trials Group (PoCoG),

NSW

Why aren't we 'Measuring what matters to cancer survivors' in Australia? Ms Julie Marker, Cancer Voices South Australia

Hospital-based supported self-management intervention for colorectal cancer survivors: Acceptability and feasibility in New Zealand
Ms Inga O'Brien, Univeristy of Otago, Wellington, New Zealand

Coping-Together: A Self-Management Intervention to Address the Psychosocial Needs of Couples Affected by Cancer

Dr Janelle v Levesque, University of New South Wales/Ingham Institute, NSW

10.30 - 11.00am	Morning Tea	Riverbank Foyer
11.00 - 12.30pm	Plenary 6 - Models of care II - from self care to prim (continued)	ary and specialist care Riverbank Rooms 7 & 8
	Session Chair: Prof Afaf Girgis, University of New South Wales	
	Supporting Cancer Survivors in Victoria: What have we learnt? Ms Kathryn Whitfield, Department of Health, VIC	
	<u>Proffered Papers</u>	
	A transferable model of survivorship care Ms Kate Schofield, Barwon Health, VIC	
	Provision of survivorship care for patients with haem completion of treatment: a national cancer nursing p Dr Raymond Chan, Royal Brisbane and Women's Ho	ractice survey
	Just the tip of the iceberg: Evaluating the impact of a service on the health literacy of cancer survivors	nurse-led survivorship

Ms Donna Lever, Barwon Health, VIC

Developing a Cancer Survivorship Monitoring System for South Australia **Dr Marion Eckert, Cancer Council South Australia**

Discussion

Launch of COSA Survivorship Model

Dr Haryana Dhillon, University of Sydney, NSW

12.30 - 1.30pm

Lunch and poster viewing (including poster awards)

Riverbank Foyer

Group photo

Poster session and awards proudly sponsored by



1.30 - 3.00pm

Plenary 7 - Connected survivorship care

Riverbank Rooms 7 & 8

Session Chairs: Ms Annie Miller, Cancer Council New South Wales Ms Danielle Tindle, Queensland University of Technology

Live cross to Townsville and Mt Isa - Associate Professor Sabe Sabesan and his team will share how regional and remote communities are being supported by telemedicine

A/Prof Sabe Sabesan, James Cook University, Townsville Cancer Centre, Townsville Hospital

Live demonstration linking

Mr Matthew Zachary, Stupid Cancer, United States

Proffered Papers

Using digital technology to empower and support people affected by cancer and health professionals

Mrs Jillian Mills, Cancer Council New South Wales

"Exergaming and Lymphoedema Management": The use of Nintendo's Wii Fit™ yoga program in the management of breast cancer-related lymphoedema

Ms Natalie Bampton, Flinders University, SA

Development and Usability of Rekindle, a web-based psychosexual resource for all cancer survivors and their partners

Dr Catalina Lawsin, University of Sydney, NSW

3.00 - 3.30pm

Afternoon Tea

Riverbank Foyer

3.30 - 4.30pm Plenary 8 - Panel discussion - Is cancer survivorship a new disease?

Riverbank Rooms 7 & 8

Facilitator: Michael Sexton, ABC TV, SA

Panel:

Mr David Chapman, Glenelg, SA
Dr Adrienne Walker, BreastScreen SA
Mr Luke Ryan, Writer, comedian and two-time cancer survivor, VIC
Ms Danielle Tindle, Queensland University of Technology
Dr Haryana Dhillon, University of Sydney, NSW
Prof Bogda Koczwara, Flinders Centre for Innovation in Cancer,
Flinders University, SA

4.30 - Close Plenary 9 - Conference Reflections

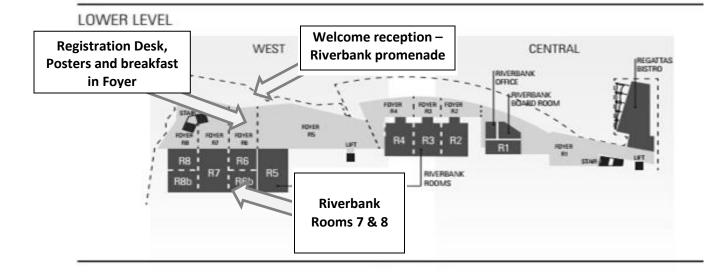
Riverbank Rooms 7 & 8

Facilitators: Ms Annie Miller, Cancer Council New South Wales Dr Haryana Dhillon, University of Sydney, NSW

Delegate Information

Venue: Adelaide Convention Centre, Riverbank Rooms, Lower Level

The multi-award winning Adelaide Convention Centre enjoys a global reputation for excellence and is consistently ranked among the world's top convention centres. The convention centre is located next to the Adelaide Railway Station and within walking distance of trams, accommodation and the CBD. If you have any questions during the meeting, don't hesitate to ask at reception or see ASN Events staff at the Conference registration desk.



Registration Desk

The registration desk will be located in the Riverbank foyer on the lower level and will be open from 7.30am to 5.00pm Friday and 7.30am to 3.30pm Saturday.

Session Rooms

All sessions will be held in Riverbank rooms 7 & 8. Breaks and posters will be held in the Riverbank foyer. The welcome reception on Friday evening will be held on the Riverbank promenade. Please refer to above map for reference.

What is included in your full registration

- Access to all sessions
- Conference book
- Welcome reception
- Morning teas, afternoon teas and lunches
- Access to the conference app

Name Tags

Delegates are required to wear their name tags to all sessions.

Social Functions

The welcome reception is being held on Friday 6th February on the Riverbank promenade at Adelaide Convention Centre from 5.30pm to 7.30pm. A BBQ dinner and beverages will be served.

Internet access at the Conference

Wireless internet is available free of charge for delegates in the conference area. There are no user names or passwords. To access free Wi-Fi, search for networks on your Wi-Fi enabled device and select 'ACC Free Wi-Fi' from the list, once connected you will be prompted to enter an email address.

Conference App

The App is displayed in a simple and easy to read format on your phone, iPad, or even your computer. To get the 'App', please open the below link in your internet browser on your phone, iPad or laptop.

http://survivorship-2015.m.asnevents.com.au/

You will be prompted to add an icon onto your device home screen. The 'App' will allow you to:

- View the full conference program
- View all abstracts for the conference
- Save your favourite sessions and plan your day
- Take notes which will then be saved and downloaded from your registration profile.

To use most of these functions, you will be prompted to 'log in' each day. Simply enter the same email & password which you used to register.

Instructions for Oral Presenters

Please upload your presentation onto the computer in the room, either on the morning of the day you are presenting, or in the break prior to your session commencing. The standard AV set up for all presentations will be data projection using MS PowerPoint. As per instructions already supplied, you will need to have your talk supplied on a USB thumb drive. If you wish to use your Macintosh please ensure you bring the appropriate projector converter cables. An ASN staff member will be there to assist you.

Instructions for Poster Presenters

Poster viewings will be held during the lunch breaks (**12.30pm** – **1.30pm**) on Friday 6th and Saturday 7th February. You are requested to stand by your poster during this time. You can mount your poster upon arrival at the conference. The maximum size provided is 1m wide by 1.2m high. The approved way of attaching your abstract is with Velcro – which is available on the poster boards provided. Please remove posters by **5.30pm** Saturday evening.

Mobile Phones

Please ensure your mobile is turned off or to silent during the sessions.

Insurance

The hosts and organisers are not responsible for personal accidents, any travel costs, or the loss of private property and will not be liable for any claims. Delegates requiring insurance should make their own arrangements.

Disclaimer

The hosts and organisers are not responsible for, or represented by, the opinions expressed by the participants in either the sessions or their written abstracts.

Smoking

Smoking is not permitted in the venue.

Local Information

Adelaide

Adelaide is the "perfect host city" and is "ready to be uncorked"...so says *Lonely Planet* which named the South Australian capital as one of the top 10 must visit cities for 2014. The city centre is surrounded by parklands and is a blend of historic buildings, wide streets, parklands, cafes and restaurants. Adelaide is easy to get around with rolling hills to the east and beaches to the west;

Head for the hills: Take a day trip to Hahndorf, one of the Adelaide Hills' most famous towns. It's Australia's oldest surviving settlement and has a strong German heritage. Stop at nearby Cleland Wildlife Park to feed kangaroos and hold a koala.

Hit the beach: Relax on a beautiful beach. Catch a tram from Adelaide to Glenelg for some fun in the sun. Enjoy al fresco dining on Jetty Road or Holdfast Marina. Go fishing on the Eyre Peninsula. Feast on oysters, lobsters and abalone. Dive in and swim with wildlife. Enjoy the antics of sea lions and the thrill of great white sharks.

Visit our National Landscapes: Admire nature on Kangaroo Island. Visit Remarkable Rocks and Admirals Arch – these rock formations are incredible! See native animals thriving in the wild, like seals at Seal Bay. Explore stunning beaches and desert dunes. See rock art, fossils and spectacular landscapes in the Flinders Ranges. Get a bird's eye view of Wilpena Pound on a scenic flight.

Head down the coast: Stop by the seaside town of Victor Harbor. Cross the causeway on a horse-drawn tram and see little penguins on Granite Island. Visit the South Australian Whale Centre or board the Cockle Train for a steam train ride. Holiday on the Murray River, an Australian icon. Hire a houseboat and see the water up close. Drop a line and go fishing. Visit Coorong National Park at the Murray River's mouth. It's a sanctuary for birds and fish.

Adelaide Oval: The redeveloped Adelaide Oval offers a unique blend of new and old, carefully integrating the latest in stadium design with famous features such as the heritage scoreboard, century-old Moreton Bay Fig trees, the grassed northern mound and more. These elements form an embedded museum, with integrated points of interest and historical features bringing the whole stadium to life. The Adelaide Oval Tours take you behind the scenes to the inner workings of this iconic ground. You will be guided through the stadium by our expert volunteer guides whose passion for the oval is infectious and their stories captivating.

Taste South Australia: Try some wine. Adelaide has more than 200 cellar doors on its doorstep. Explore the Barossa Valley, Australia's most famous wine region. Drink the world's best Riesling in the Clare Valley. Catch your breath in our beautiful parks and gardens. Adelaide Botanic Garden is a haven in the heart of the city.

Local Attractions

Adelaide Night Life

Apothecary: 118 Hindley St, Adelaide **Casablabla:** 12 Leigh St, Adelaide

Duke of York Hotel: 82 Currie St, Adelaide **Supermild Lounge Bar:** 182 Hindley St, Adelaide

Udaberri: 11 Leigh St, Adelaide

Adelaide Restaurants

Africola: 4 East Terrace, Adelaide Cliché: 26 O'Connell St, North Adelaide Paddy's Lantern: 219 Gilbert St, Adelaide La Rambla Tapas Bar: 28 Peel St, Adelaide

Sean's Kitchen: SkyCity Casino, Station Rd, Adelaide

Surrounding Attractions

Barossa Valley

Just over an hour drive from Glenelg is the Barossa Valley Wine Region. The Barossa has cool summers and rainy winters which make it perfectly suited for red wine production, particularly Shiraz and richly flavoured Cabernet. The fertile soil of the Barossa is home to some of the world's most lauded vineyards. For more information on the region, visit: www.barossa.com

Kangaroo Island

Minutes from the mainland, but a million miles away, Kangaroo Island is a sanctuary for wildlife and natural, rugged beauty. It is the perfect place to disconnect from the world and reconnect with what and who is truly important to you. Escape to an island you will never want to leave.

For more information on kangaroo Island, visit: www.southaustralia.com/regions/kangaroo-island.aspx

Port Adelaide

At Port Adelaide, find evocative seafaring history, a waterside heritage precinct, a colourful pub scene and the world's only inner-city dolphins – only a half an hour drive from Glenelg. Take a walk along the docks and through the 'old Port' to experience the ambience and observe some of the finest colonial and Victorian buildings in Australia.

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Abstracts

Printed abstracts reflect the views of the authors

Ahs # 1

Two years later - what has changed?

Bogda Koczwara¹

1. Flinders Centre for Innovation in Cancer, Bedford Park, SA, Australia

The inaugural Flinders Survivorship Conference in 2013 started the conversation on the issues of cancer survivorship in Australia and around the world. We, the conference attendees, had great desire for meaningful change and ambition for progress. How well did we realise these? It seems that last 2 years have been a period of significant growth in the field of cancer survivorship with emerging research into specific needs of cancer survivors, development of national collaborations and engagement with international colleagues. But there is plenty of work to be done and plenty of unaddressed gaps that warrant attention. This presentation will review progress in the field of cancer survivorship over last 2 years and consider how the present meeting can best contribute to progress in the discipline in Australia and beyond.

Abs # 2

Surviving is not enough

Sally Crossing AM¹

Cancer Voices, Greenwich, NSW, Australia
 Ashleigh Moore Oration

Ahs # 3

Life beyond a cancer diagnosis: Mere survival or meaningful survivorship?

Leonie Young¹

1. Australia & New Zealand Breast Cancer Trials Group, Brisbane, QLD, Australia

Research into cancer survivorship and the development of survivorship care plans are important and are welcomed advancements in the management and care of people diagnosed with cancer, however, a considerable amount of these focuses on the physical, health and economic issues. People affected by cancer need more than mere survival strategies and even though information is literally at our fingertips, they still struggle to find meaningful survivorship beyond their diagnosis.

The data on survival is given in terms of five-years and monitoring is undertaken during this period, yet there are a large number of people who are living outside of the five-year time line.

A patient confronted with cancer, commences on a narrative path. This narrative, described as a time of finding meaning, charts the ways patients learn about their condition, how they make meaning of it, construct an identity as a patient, and an identity as someone who was a patient once. This last phase is where the challenges lie — how to find meaningful survivorship beyond the cancer diagnosis. This pathway involves a story of negotiation and participation. It involves the person as an individual with an identity, becoming a patient, often de-identified, back to being an individual, but changed. The change may be significant or subtle and so the narrative, the person's story, charts the negotiation and re-negotiation of meaning. (Roos, I. 2005 unpublished discussion)

What are the barriers for people finding meaningful survivorship and importantly, what are the solutions?

Abs # 4

Dealing with the sword of Damocles

Michael Jefford¹

1. Australian Cancer Survivorship Centre, Peter MacCallum Cancer Centre, Melbourne, VIC, Australia

Fear of cancer recurrence (FCR) is a common concern amongst cancer survivors. It may feel like the sword of Damocles – an ever-present threat, dangling above them, held only by a hair.

This presentation will focus on the recently-produced clinical practice guideline (CPG) 'Recommendations for the identification and management of fear of cancer recurrence in adult cancer survivors' developed by Cancer Australia.

The 'Clinical practice guidelines for the psychosocial care of adults with cancer' were developed in Australia and released in 2003. In 2011 FCR was identified as a topic missing from the 2003 CPG. A supplementary CPG was thus developed.

A systematic review was undertaken. Key questions were:

- 1. What is the prevalence of FCR in cancer patients?
- 2. What are risk factors for having FCR?
- 3. What is the impact of FCR on wellness?
- 4. What interventions are effective in dealing with FCR?

A multidisciplinary working group provided comment on the systematic review, advised on content and assisted with dissemination of the CPG.

The review found that FCR is experienced by the majority of cancer survivors and may be a long-lasting concern. It was the most commonly reported concern in a number of studies. People frequently report an unmet need for assistance.

FCR appears more common in younger people, in women and in those with more physical symptoms, psychological issues or advanced disease. FCR is associated with lower quality of life, including emotional and physical functioning, and more frequent reassurance seeking. It may, though, be linked to positive behaviour change. Lower FCR is linked with having religious or spiritual beliefs, adequate social support and sense of optimism.

A small number of studies have assessed the impact of interventions for FCR. Some interventions appear to reduce FCR. Cognitive behavioural therapy and supportive expressive therapy appear to result in sustained benefits.

More research is required around FCR. Topics might include (1) what are effective strategies to identify people with bothersome FCR? (2) what strategies are effective at reducing FCR and associated poor quality of life? (3) what strategies can be scaled to large numbers of people?

See http://canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/recommendations-identification-and-management-fear-cancer-recurrence-adult-cancer-survivors

Abs # 5

Building resilience in the *state of wellbeing*: measurement, interventions, transmission, evidence and community in a life course approach

Gabrielle Kelly¹

1. SAHMRI, Adelaide, SA, Australia

Building upon the recommendations of *Adelaide Thinker in Residence* Professor Martin Seligman, South Australia is set on becoming known as the *State of Wellbeing*, using a public health approach to build mental health and resilience skills in the whole population.

Seligman tells us that it is now possible to measure wellbeing using his framework of wellbeing PERMA – positive emotion, engagement, relationships, meaning and accomplishment. Finally we will be able to measure the efficacy of the many different interventions currently used or proposed, to build mental health assets, wellbeing and resilience in humans. South Australia has decided to measure some other key factors: *PERMA+*, all the PERMA categories plus resilience, optimism, physical activity, nutrition and sleep.

Hundreds of South Australian individuals and organisations are investigating or embracing this vision. How is it going? Is it systematic? Who are the leaders? Are hubs emerging? What is the measurement approach? What is the science behind the interventions or approaches? How is it scaleable? How is fidelity of model being approached? Who is managing the data?

These and many other questions are asked and answered in a broad-ranging keynote against the context of building the State of Wellbeing- the first political unit in the world to measure and build wellbeing.

Abs # 6

Developing cancer survivor stories, personal narratives told to and written by a cancer consumer.

Linda Nolte¹, Meg Rynderman¹, Michael Jefford^{1, 2}

- 1. Australian Cancer Survivorship Centre, Peter MacCallum Cancer Centre, Melbourne, VIC, Australia
- 2. Department of Cancer Experience Research, Peter MacCallum Cancer Centre, Melbourne, VIC, Australia

Background

Reading about the experiences of others is an important and common way for cancer patients and survivors to gather information and support. Many survivors seek out personal narratives regarding the consequences of cancer, how others have interpreted the meaning of this experience, their reflections and coping strategies. These stories may help normalise experience, empower others and promote resilience. In 2012, Meg Rynderman a cancer survivor and volunteer with the Australian Cancer Survivorship Centre (ACSC) documented her own cancer journey, experiences and reflections for others to read. ACSC sought to develop further stories.

Δim

To develop a series of cancer survivor stories, which aim to capture the physical, emotional, social and financial consequences of cancer treatment, capture the meaning of this experience, and personal reflections.

Method

In 2013, ACSC sought to capture the stories of a range of survivors. A number of survivors were approached and their consent was sought to participate in a face to face consumer-led interview (with MR). An interview framework was developed following multidisciplinary consultation. Open-ended questions explored survivors' experiences during and after treatment. Personal narratives were reviewed by a multidisciplinary group, professionally edited, and reviewed and verified by the cancer survivor.

Survivors provided consent for ACSC to publish their story, together with photographs, and distribute the story electronically and in print. Stories were produced in 4-page A4 portable document format (PDF).

Discussion

To date five stories have been developed and more than 800 copies have been distributed in hard copy via the Australian Cancer Survivorship and Information Centre at the Peter MacCallum Cancer Centre and through other Victorian cancer services. Survivor stories are available at http://www.petermac.org/stories-people-impacted-cancer. Informal feedback suggests that they represent an important resource for survivors, family members and caregivers. ACSC plans to develop further stories.

Abs # 7

Conceptualisation of post-treatment survivorship: experiences from different cultural groups

Clare O'Callahan 1,2,3, Penny Schofield Phyllis Butow, Linda Nolte, Spiri Tsintziras, Melanie Price, Michael Jefford, 6

- 1. Cabrini Health, Malvern, VIC, Australia
- 2. Caritas Christi Hospice, St Vincent's Health, VIC, Australia
- 3. Department of Medicine, University of Melbourne, VIC, Australia
- 4. Department of Cancer Experiences Research, Peter MacCallum Cancer Centre, Melbourne, VIC, Australia
- 5. School of Psychology, University of Sydney, NSW, Australia
- 6. Australian Cancer Survivorship Centre a Richard Pratt legacy, Peter MacCallum Cancer Centre, Melbourne, VIC, Australia

Background

Immigrants diagnosed with cancer face multiple challenges within an unfamiliar health system. There is limited information about how the concept of survivorship is conceptualised by cancer survivors from Culturally and Linguistically Diverse (CALD) backgrounds. To understand the issues faced by CALD cancer survivors, we conducted focus groups with individuals from Chinese and Greek nationalities.

Strategy

Cancer survivors whose native language was Mandarin, Cantonese or Greek were identified through ethno-specific cancer support groups and cancer specialists in two states of Australia. Focus groups were facilitated by researchers in the participants' native language and followed a semi-structured interview format. Focus groups were taped, transcribed and analysed for principle themes.

Outcomes

Six focus groups were conducted involving 41 CALD cancer survivors. There was an overall antipathy to the term "survivor," with the term "recovery" preferred. Participants from all three language groups expressed a strong desire for practical information following treatment particularly related to changes in lifestyle, as well as information about ways to cope with the physical and emotional consequences of treatment. All requested more information in their own language and all had a preference for written material.

Learnings

The findings emphasise that people treated for cancer from CALD communities have overlapping but distinct requirements compared with those of the native community. It is not sufficient to translate materials into the relevant language.

Abs # 8

Resilience following breast cancer treatment - findings from a prospective study

Barbara Bennett^{1, 2}, David Goldstein^{1, 2}, Michael Friedlander², Kate Webber^{1, 2}

- 1. NSW Cancer Survivors Centre, Sydney, NSW, Australia
- 2. Medical Oncology, Prince of Wales Hospital, Sydney, NSW, Australia

Introduction: A cancer diagnosis is often regarded as a potentially traumatic event with untoward consequences thus discounting the human capacity for resilience - 'the ability to maintain relatively stable functioning following an aversive life event'. Predictors of resilience in women who recovered uneventfully from surgical and adjuvant treatment for early-stage breast cancer were investigated prospectively.

Methods: Women completed self-report measures of mood, somatic symptoms, temperament, illness attitudes, and social support, post-surgery. At end-treatment, 1, 3, 6, 9 and 12 months post-treatment completion, measures of mood and somatic symptoms were self-reported. Clinical, tumour and treatment details were recorded. Resilience was defined as: no evidence of protracted psychological or somatic distress in the 12 months following treatment completion, and predictors sought by logistic regression.

Results: Almost half the women had no long-term disturbance, with 34% classified as resilient and a further 15% recovering quickly from treatment. Clinical and treatment variables did not predict outcome. Those identified as 'resilient' reported higher perceived social support and exhibited low emotional reactivity. They consistently rated their overall quality of life higher.

Conclusions: Identified predictors of resilient outcome in women following diagnosis and treatment for early stage breast cancer lend support to findings of other investigators(1) who assert that resilience is the most common response to a potentially traumatic event. Clinical implications of these findings highlight the importance of early identification of those in need of interventions to improve quality of life outcomes.

Ahs # 9

"More than just telling my story" when cancer survivors become teachers.

Julie Marker¹, Louise Bastian¹, Stephanie Newell¹, Kathryn Lockier¹

1. Cancer Voices South Australia, Kensington Park, SA, Australia

Introduction

The 'Cancer Survivors as Teachers' initiative aims to increase health professionals understanding about the all-encompassing impact cancer can have on individuals and their family, along with the toll on their emotional, physical, practical, and financial lives. In interactive sessions designed to provide an intimate learning experience, cancer survivors share their personal insights and 'tips for providing good cancer communication', together with any 'positives' from their cancer journey. This is much more than 'just telling your story'.

Methods

Over the past 3 years Cancer Voices SA have arranged and supported survivors and carers to work in 'teams' to prepare and present an annual series of 12-15 one-hour interactive tutorials with small-groups-of-8 medical students. Additional sessions with pharmacy and nursing students, oncology post-graduate nurses, psycho-oncology researchers and chemotherapy unit nursing staff have also been held.

Our 'team' methodology has, in addition to the main speaker (teacher), one or two support person(s) to facilitate and 'chip-in' their additional viewpoints on cancer survivorship.

Debriefing and feedback from speaker/teachers is undertaken afterwards by the 'team', and feedback is sought from the student or staff supervisors by Cancer Voices SA.

Outcomes

Cancer Survivor Teachers report finding it rewarding and, at times, cathartic to be assisting in the development of health professionals, and 'giving back' to help future cancer survivors.

Our support and 'team' methodology contributed to increased confidence and satisfaction of the 'teachers', along with increased awareness of the diversity of other cancer survivor experiences.

Survivors' knowledge and insights wrought from their cancer experience(s) have been found to richly contribute to the classroom and in-service curriculum for health professionals.

Positive evaluation from student feedback and reflective writing exercises has resulted in these interactive 'Cancer Survivors as Teachers' tutorials now being firmly embedded in one medical school curriculum(1).

 Thomas J, Vitry A, Marker J. Students perceptions of a consumer-led discussion group format to improve awareness of the patient perspective (poster) Clinical Oncology Society of Australia (COSA) Conference Nov 2013. http://www.cancervoicessa.org.au/assets/documents/posters/cosa%20poster%20final.pdf

Abs # 10

ICF Core Set Development for Lymphoedema in Australia

<u>Shannon Vanderstelt</u>¹, Malou van Zanten², Kate Bryson², David Hancock³, Anna Herbert¹, Bridget Lloyd-Fox¹, Rebecca Walley¹, David Warncken¹, Kathleen Wang¹, Peter Viehoff, Neil Piller^{2, 1}

- 1. School of Medicine, Flinders University, Bedford Park, South Australia, Australia
- 2. Lymphoedema Research Unit, Flinders Medical Center, Bedford Park, South Australia, Australia
- 3. School of Medicine, Flinders University, Bedford Park, South Australia, Australia

Introduction: The International Classification of Functioning, Disability and Health (ICF) is a World Health Organisation (WHO) initiative that assists in measuring health and disability at both the individual and population level. Core sets of ICF questions have been developed for breast cancer and other individual (chronic) conditions. These core sets provide health care professionals with targeted questions to ask to determine factors in a patient's life that are most likely influenced by that disease. An ICF core set has yet to be developed for lymphoedema, a chronic, debilitating condition secondary to cancer treatment.

Study Aims: To determine the most common factors and activities of daily living that are affected in individuals with lymphoedema in South Australia and develop an ICF core set for lymphoedema.

Subjects and Methods: This study is part of an international 29multicentre cross-sectional study. Participants were drawn from the Lymphoedema Research Unit at Flinders Medical Center and Lymphoedema and Laser Therapy Clinic. The participants completed three questionnaires about their health and quality of life followed by a face to face conversation based interview. The interview involved questions from the ICF tool about their body functions and structures, activity and participation limitations, environmental factors and socio-demographic status.

Results: The study is ongoing. 107 participants have been interviewed to date. Most limitations are in the area of activity and participation and changes in body function and structure of the affected area. The location of lymphoedema affects the impact of the condition on the quality of the lives of the participants.

Conclusion: Development of an ICF core set for lymphoedema will help researchers and health professionals understand to what extend lymphoedema is affecting their patient. It will also help gain more recognition for lymphoedema as a significant condition by a wider community of health care providers.

Abs # 11

Addressing the gap- meeting the long term survivorship and rehabilitation needs of women living with secondary breast cancer.

Danielle Spence¹, Michelle Marvin¹, Kathy Wells¹

1. BCNA, Camberwell, VIC, Australia

Background

It is estimated that approximately 9000 Australian women are currently living with secondary breast cancer. New and emerging treatments are resulting in substantial long term survival benefits in selected groups of women. As a consequence some women are living with relatively stable disease, at times for many years. For others, secondary breast cancer is a long-term chronic health condition involving multiple treatments over time that can lead to long lasting functional limitations.

Method

In August 2014, Breast Cancer Network Australia conducted a survey of over 580 women living with secondary breast cancer to identify their unmet supportive care, financial, practical and information needs.

Results

Results showed that long term treatment side effects were significantly impacting on women's physical and emotional well-being. Common issues identified were similar to needs of women with early breast cancer. Over 45% of women expressed concerns around uncertainty about the future; around 54% of women expressed concerns around managing fatigue. Many women reported having minimal contact with health professionals they felt they could talk to about self-care strategies to assist them to maximise their ability to live well.

Conclusions

The current model of survivorship care focuses on women with early breast cancer perceived to be free of disease. This approach lacks attention to the concerns of women with secondary breast cancer who are experiencing similar supportive care needs. BCNA's survey has identified a rehabilitation need to improve the quality of survival for a broader group of cancer survivors including women living with secondary breast cancer.

This presentation will discuss the key unmet needs identified in our survey. As women with secondary breast cancer continue to live longer, we will propose that survivorship and rehabilitation services should extend their programs to include women with incurable disease to assist them manage their illness and lead fulfilling lives.

Abs # 12

What is the effect of nutrition interventions on long term cardiovascular and metabolic parameters in cancer survivors and patients?

Danielle Brown¹, Bogda Koczwara², Michelle Miller¹

- 1. Flinders University, Adelaide
- 2. Flinders Centre for Innovation in Cancer, Adelaide

Background

The role of nutrition in the prevention of cardiometabolic illnesses and cancer is well established, however little is known about the impact of nutrition on the risk of cardiometabolic illness developing following cancer and its treatment.

Aim

To determine the effect of nutrition interventions on long term cardiovascular and metabolic parameters in cancer survivors.

Methods

Systematic review of randomised controlled trials in which a nutrition intervention was implemented in cancer survivors/patients and reported on either a cardiovascular and/or metabolic outcome over >3 months of follow-up.

Results/discussion

From the 1,551 articles retrieved from the databases Medline and Medline In Process, Scopus and CINAHL, 18 met the selection criteria and were included in the review. Nutritional interventions were categorised as either general healthy eating, modification of energy intake, supplement/extract intake or individualised dietary advice. Of the included studies, 11 reported significant improvements in at least one cardiometabolic outcome between groups or the presence of a relationship from the interventions general healthy eating, modification of energy density or individualised dietary counselling. Alteration of energy density in cancer patients/survivors had the largest effect, which consistently achieved improvements in body weight (ranging from -0.05kg to -5.7kg) and anthropometric measures. A general decrease of energy intake appeared to generate more significant results than a focus of reducing fat intake. Studies were limited by use of self-reported measures and the majority being conducted on breast cancer patients/survivors meaning the results may not be generalisable to other cancer types or males.

Conclusions

Alteration of energy density and general healthy eating interventions appear to have to greatest effect on cardiometabolic outcome in cancer survivors. More randomised controlled trials need to be conducted utilising non self-reporting measures in a range of cancer types in order to strengthen the body of evidence.

Abs # 13

Improving bone health of cancer survivors - a complex implementation problem

Bogda Koczwara¹

1. Flinders Centre for Innovation in Cancer, Bedford Park, SA, Australia

Background: Cancer survivors are at increased risk of bone loss as a result of cancer treatment with breast and prostate cancer survivors most commonly affected. While assessment and management of bone loss after cancer is supported by multiple guidelines, it is unclear how best to implement these guidelines into clinical practice. This presentation will examine a multilevel analysis of barriers and potential enablers to delivery of bone health management to cancer survivors and how these may impact on the implementation of guidelines in this area.

Methods: Multiple methods of data analysis were applied including qualitative methodology to obtain feedback from stakeholders, evaluation of current practice patterns, quality of evidence, cost effectiveness data and reimbursement patterns. Based on these a conceptual analysis incorporating barriers and enables have been developed.

Results: The key barriers to practice relate to 1. quality of evidence (consensus guidelines with variability between different guidelines, use of bone density as surrogates for fractures, difficulty estimating effectiveness and cost effectiveness of interventions in the target population), 2. access to evidence and to interventions (bone density tests and bisphosphonate treatment) and 3. lack of consensus among providers of who should be delivering care and how. Of those the issue of quality of evidence is the hardest to

Conclusions: Bone health management for cancer survivors presents a challenging problem of implementation barriers in a complex setting of care delivery. Successful delivery of survivorship care required multilevel strategies to address these barriers.

Abs # 14

What Is Important To Research: The Cancer Survivors' Voice

Sharon Lawn¹, The Fleurieu Cancer Netword (FCN)², Bogda Koczwara³

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Health service users' involvement in research has traditionally been as 'subject' or 'object', with little consultation about how research problems are defined and prioritised. In a period of ever decreasing research resources, researchers are increasingly required to conduct and demonstrate research that has genuine translational value. An important component of this is the requirement to make consumer involvement in the research process more explicit and meaningful. This study involved a focus group with 18 cancer survivors who came together to discuss what they perceived as the priority issues for cancer survivorship research and how researchers could involve them more effectively and meaningfully in research. Participants discussed what they need to survive well, how they want medical surveillance to improve, and what they want researchers to know about their progress over time. Cancer health literacy for cancer survivors, families, the wider community and health professionals was unanimously identified as a priority research theme. Other themes included understanding the importance of peer support, a holistic perspective that includes physical and emotional wellbeing, the role of family and carers, return to work issues, and the journey of comorbidity and monitoring long-term. These themes will inform the research agenda for the Flinders Centre for Innovation in Cancer as it works with cancer survivors to building its focus on cancer survivorship research.

Abs # 15

A Nurse-Led Lifestyle Intervention for Endometrial Cancer Survivors.

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- 2. School of Population Health, The University of Queensland, Herston, QLD
- 3. Lifehouse Cancer Centre, Camperdown, NSW

Background: Endometrial Cancer is now the most common gynaecological cancer in Australia and continues to rise in incidence¹. This increase is largely attributed to risk factors such as obesity, diabetes and hypertension, common comorbidities in these women². While cancer cure is frequently achieved, many remain at high risk of premature death³. Oncology nurses may help ameliorate the effects of comorbidities through the delivery of lifestyle interventions.

Aim: The aim of this research was to investigate the feasibility of a nurse-led lifestyle intervention for endometrial cancer survivors. **Method:** Pre and post evaluation with the RE-AIM framework⁴ was used to determine feasibility, through evaluation of, Reach; Efficacy; Adoption; Implementation and Maintenance. The Active Australia Survey⁵ and the Dietary Behaviour Questionnaire⁶ measured physical activity and dietary behaviour at baseline, one month and six months.

Intervention: The nurse-led intervention included Motivational Interviewing⁷, the 5A's approach⁸, tailored print material⁹, and referral to the "NSW" Get Healthy Coaching Service¹⁰.

Results: Twenty participants were recruited with one drop out at six months. Compared to baseline, improvements were found in total dietary behaviour at one month (p=.002) and six months (p=.036). Median minutes of continuous walking doubled at six

months (p=.026) but no statistically significant findings were found for vigorous (p=.176) or more moderate activity (p=.138). The improvements in dietary behaviour and exercise from baseline to six months suggest some maintenance of lifestyle modification by participants.

Conclusion: Results from this study are promising, suggesting that the nurse-led intervention is feasible. However, many of the participants were already exercising prior to the intervention, limiting reach. Adoption and implementation was supported in this single study site but more research with greater sample sizes, in a variety of settings, is needed to ensure generalizability to the wider population.

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Abs # 16

Finding My Way: An interim analysis of predictors of adherence to an internet self-help program for cancer-related distress.

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Background

Online self-help interventions hold promise for overcoming access barriers to conventional psychotherapy for cancer distress. However, a key limitation in the provision of online interventions generally is low adherence, with few clear predictors of adherence identified in the literature. This presentation reports on a mixed-methods interim analysis of predictors of adherence to the two intervention conditions being trialled (treatment and attention-control), as part of a larger NHMRC-funded RCT.

Methods

Data from cancer patients treated with curative intent who had completed the Finding My Way program by the end of June 2014 (n = 60) were analysed according to predictors of adherence. Measures of adherence included number of modules accessed, days logged in, number of logins, total login time, and pages viewed. Potential predictors under evaluation included baseline demographic, illness, and psychosocial variables. A further subset of participants (n = 13) provided qualitative interview feedback on motivators and barriers to using the program, which underwent thematic analysis.

Results

Adherence was high, with 43 participants (72%) accessing four or more of six modules. Group comparisons of low versus high adherers revealed high adherers were significantly more likely to be control-group members and had higher levels of social support. Multivariate analyses indicated higher adherence was predicted by control group membership, higher social support, less endorsement of a blunting coping style, and higher health service use. Interview data suggested adherence motivators included intervention factors, personal factors, psychological factors, and research participation, while barriers included cancer treatment side effects, timing, intervention factors, computer-related factors, personal factors, and psychological factors.

Conclusion

This study successfully identified several predictors of, and motivators and barriers to, cancer patients' adherence to an online intervention for cancer-related distress. This work was funded by NHMRC Project Grant #1042942.

Abs # 17

What are cancer survivors attending the Sydney Survivorship Clinic like and what do they need?

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Background

The Sydney Survivorship Centre was established September 2013, to provide holistic care for adult cancer survivors. It provides a multi-disciplinary clinic (involving cancer specialist, cancer nurse, dietitian, psychologist and exercise physiologist) for patients with localised cancer (breast, colorectal, haematological) completing primary treatment(s). Lifestyle interventions, classes, public forums, and support groups are offered as adjuncts. Here we report the status of patients presenting to the clinic during its first year.

Method:

Survivors completed questionnaires assessing: distress, symptoms, quality of life, diet and exercise before attending; and a satisfaction survey after. Additional information: demographics, body mass index and recommendations from the clinic were reviewed and participation in subsequent programs evaluated.

Results:

Survivorship clinic was accessed by 100 new patients from September 2013 to 2014: median age 54 years (range 23-80); 78% were female. Median time from diagnosis: 11 months (range 1-134). 51% had been diagnosed with breast cancer, 35% colorectal and 14% haematological malignancy. Most common symptoms of at least moderate severity were: fatigue (50%), anxiety (40%), depression (32%). Distress Thermometer mean score was 3.6/10 (range 0-10), with 43% scoring >4. After review our psychologist recommended 45% of attendees commence or continue with psychological follow-up.

Average body mass index (BMI) was 28.1 kg/m² (range 17.6-59kg/m²); 61% were overweight or obese, with mean weight gain since diagnosis of 2.9kg (range: -10.3-24.65kg). 42% of survivors reported meeting physical activity guidelines; those who did not were referred to various exercise interventions, including courses run through the Survivorship Centre.

92% rated attendance at the Survivorship clinic as 'extremely' or 'very worthwhile' and 81% would recommend the clinic to others.

Conclusion:

Distress, anxiety, fatigue, obesity and sedentary lifestyle are common in our cancer survivors. The Survivorship clinic has the potential to address important issues for cancer patients after adjuvant treatment.

Abs # 18

Complementary therapies - exploring preferences to inform a model of care

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- 2. Peter MacCallum Cancer Centre, Bendigo, Vic, Australia

Background: Psychosocial support, which may include complementary therapies, has the potential to improve healthcare outcomes, reduce emotional distress, and improve satisfaction with care¹. A study of Australian cancer patients investigating preferences on the integration of complementary therapy with conventional cancer care found that patients achieved a sense of autonomy and self-expression through use of complementary therapies².

Our East Melbourne campus offers a limited integrative therapies program which includes reflexology, hand and foot massage, meditation and music therapy. The program is offered to patients and their carers. Little is known about why people use or do not use the program.

Aim: To collect quantitative data about current complementary and alternative medicine (CAM) use by people affected by cancer and their preferences regarding therapies provided in the hospital (integrative therapies). This data will inform the development of recommendations to improve the existing integrative therapy program at Peter MacCallum Cancer Centre.

Method: Participants are invited to complete a paper based survey while attending the hospital. Participants include patients and their carers attending Specialist Clinics, Radiation Therapy, Chemotherapy Day Unit or inpatient wards.

Discussion: Recruitment commenced in October 2014 and at the time of writing 175 surveys had been returned. Final results will be presented. Results will include a breakdown of current CAM use, disclosure of CAM use to health professionals, preferences regarding provision of a range of CAM near home or at the hospital, willingness to pay, and priorities regarding complementary therapies delivered in a hospital setting.

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Abs # 19

Late effects - what can we learn from survivors of childhood cancer?

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The past half-century has seen a remarkable increase in the number of children surviving cancer, with the current overall cure rate being around 70%. However, the drugs, surgical procedures, and radiation therapy that have been necessary for this dramatic improvement may be associated with significant side-effects, and a number of these may not become evident until years after treatment. These late-effects of treatment can affect a variety of organ systems, and include second malignancies, organ dysfunction, endocrine and metabolic disorders, impaired fertility, and educational and psychosocial problems. They may be associated with substantial morbidity and sometimes can be life-threatening. Given that childhood cancer survivors potentially have many decades of life ahead of them, late effects can have a considerable impact on the survivor's quality of life as well as creating an additional burden on the health care system. As such, it is important that the risk of late effects is considered carefully when planning upfront cancer treatment, and that systems are implemented to monitor for their development during follow-up. Recently there has been international momentum to harmonise guidelines for the long-term follow-up of childhood cancer survivors, as well as a number of research initiatives relating to the prevention, surveillance, and management of late effects. Many of these finding also have implications for survivors of adult cancers.

Abs # 20

Supporting Healthy Lifestyles among Cancer Survivors - The Intersection of Population-based and Clinical Approaches

Elizabeth Eakin¹

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With growing numbers of cancer survivors worldwide, there is an imperative, from both public health and consumer perspectives, to implement evidence-based approaches that lead to improved health outcomes for survivors. Promoting healthy lifestyles is a key aspect in this regard.

A strong and consistent evidence base supports the benefits of physical activity in the post-diagnosis phase, including epidemiologic evidence of improved survival and clinical trials evidence of improvements in numerous indicators of both physical and emotional functioning, including reductions in the number and persistence of treatment-related side-effects. A more recent evidence base is beginning to show similar survival and quality of life benefits for achieving and maintaining a healthy weight following diagnosis. However, the majority of cancer survivors are insufficiently active and overweight, and the evidence base on effective lifestyle interventions is not being systematically implemented as part of survivorship care.

There are significant barriers to the uptake of effective lifestyle interventions into practice. These include the lack of policy, practice-based structures and pragmatic tools to support systematic integration into cancer care, as well as remaining evidence gaps. There are also opportunities to move forward, with successes in tobacco control utilising both population-based and clinical approaches providing guidance. In terms of supporting healthy lifestyle among cancer survivors, it will be argued that interventions that sit at the intersection of population-based and clinical approaches may provide a possible solution. The Healthy Living after Cancer program, a national translational initiative targeting physical activity, healthy eating and weight control in cancer survivors, will be presented as an exemplar. Here, researchers have partnered with state-based Cancer Councils who will deliver an evidence-based lifestyle intervention via their 13 11 20 Cancer Support and Information Service. In this context, a clinically-focussed intervention has been upscaled for delivery at the population level.

Abs # 21

Genes, survival, and survivorship.

Graeme Suthers¹

1. Sonic Healthcare, Kent Town, SA, Australia

Cancer is as inevitable as gravity. As we age, genetic errors accumulate inexorably in our bodies because of fundamental physical laws. This rate of "genetic rusting" varies between people because of genetic and environmental factors, and these factors account for much of the variation in the risk of cancer developing by a certain age. But irrespective of these factors, cancer becomes inevitable if a person lives long enough.

Improvements in diagnosis and therapy mean that many people now survive a diagnosis of cancer. Nonetheless, their genes will continue to rust. It may be possible to modify the drivers of this genetic rusting to slow the process, but it cannot be prevented. If a cancer survivor lives long enough, a second cancer diagnosis becomes inevitable. That cancer may also be successfully treated, but the rusting continues.

The inevitability of our rusting genes means that survival cannot be an end in itself. As mortal finite beings, what ultimately matters is the quality of our surviving and what we do with it.

Abs # 22

Genetic associations and trajectories of fatigue and other symptom domains after breast cancer treatment: Results from a prospective cohort study.

Kate Webber, Barbara K Bennett¹, David Goldstein¹, Andrew Lloyd¹

1. NSW Cancer Survivors Centre, University of New South Wales, Sydney, NSW, Australia

Background: We have previously reported on the natural history of cancer-related fatigue and other symptoms after adjuvant breast cancer therapy in a prospective cohort study¹. This paper reports genetic associations with symptom phenotypes.

Methods: Women with early breast cancer from six Sydney hospitals were enrolled post-surgery but before adjuvant therapy and followed with self-report questionnaires concerning physical and psychological health. Participation in a genetic association substudy was optional. Symptom scales for pain, fatigue, depression, anxiety and neurocognitive difficulties were derived by principal components analysis from end-treatment questionnaires. Genetic associations were sought with functional single nucleotide polymorphisms (SNPs) in cytokine genes tumour necrosis factor (TNF)- α , interferon- γ , Interleukin (IL)-10, IL-6, IL-1B, neuropeptide Y and the purinogenic transporter gene P2RX7.

Results: Questionnaire data at end-treatment was available for 210 participants, of whom 111 were unambiguously Caucasian with samples for genetic analyses. On multivariable analyses, independent risk genotypes were identified for each of the symptom domains (fatigue IL-6 -174 GG/GC, IL-10 -1082 GG and P2RX7 rs1718119 GG; depression and anxiety IL-10 -1082 AA and P2RX7 rs208294 AA; neurocognitive difficulties TNF- α -308 GG; pain P2RX7 rs1653624 TT and P2RX7 rs1718119 GG). Younger age was a risk for depression and anxiety, and working >20hours per week for fatigue and pain. No cancer or treatment related factors were independently associated with any of the symptom domains. The identified SNPs had cumulative effects on time to recovery from symptoms (eg for fatigue, 0 months for 0-1 risk genes vs 6 months for all three, p=0.015).

Conclusions: Susceptibility to common symptoms after cancer therapy has a genetic basis, which also contributes to risk of prolonged recovery in a cumulative fashion. As cancer and treatment factors were non-contributory, the observed findings may represent inherent susceptibility to these symptoms rather than a response unique to cancer or its treatment.

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Abs # 23

Metabolic complications in childhood cancer survivors

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- 2. School of Women's and Children's Health, University of New South Wales, Kensington, New South Wales, Australia
- 3. New South Wales Cancer Survivor Centre, University of New South Wales, Kensington, New South Wales, Australia
- 4. Inflammation and Infection Research, School of Medical Sciences, UNSW, Sydney, NSW, Australia

Background:

Childhood cancer survivors (CCS) have an increased prevalence of long-term chronic conditions, including an increased risk of metabolic syndrome, which may result in increased morbidity and mortality in CCS.

Aims:

We investigated possible mechanisms responsible for the development of metabolic complications in CCS.

Methods:

We studied 78 CCS, 16 years or older, and in remission for at least 5 years. Participants were grouped based on treatment with total body irradiation (TBI) or no irradiation (non-IRR). Anthropometric data was collected, lipid and glucose profiles were established and the incidence of insulin resistance calculated. Circulating levels of pro and anti-inflammatory cytokines were measured. Peripheral blood mononuclear cells' (PBMCs') polarised activation was assessed using flowcytometry, as well as intracellular signalling activation upon mitogen activation. Global DNA methylation was measured in different PBMC sub-types using flowcytometry.

Results:

The TBI group was characterised by impaired glucose metabolism and increased prevalence of insulin resistance. The same group also showed increased circulating levels of pro-inflammatory cytokines. PBMCs from the TBI group showed preferential Th1 polarised activation upon mitogen stimulation which was linked to increased activation of the mitogen activation protein kinase p38, as well as mammalian target of rapamycin complex 1. The over activation of those two signalling pathways was not due to a direct action of irradiation but rather a bystander effect. We identified a very specific epigenetic signature in T helper and T cytotoxic cells in CCS treated with TBI.

Implications:

Our results suggest that metabolic complications in childhood cancer survivors treated using TBI are linked to systemic and long-lasting inflammation, potentially due to the hyper-activation of intracellular signalling pathways. This long-term memory effect of irradiation could be explained by epigenetic changes. These alterations could represent useful markers for early identification of survivors at risk of developing metabolic and associated complications.

1. Neville, Kristen A., Cohn, Richard J., Steinbeck, Katharine., Johnston, Karen., Walker, Jan L.. Hyperinsulinemia, IGT and DM in survivors of childhood cancer: prevalence and risk factors. J Clin Endocrinol Metab. 2006: 91(11):4401–4407.

Abs # 24

Cutting Through the Fog: Nurses' Perceptions of Cancer-Related Cognitive Impairment

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Background:

Cognitive impairment after cancer and chemotherapy is common and distressing. Impairments are generally subtle, affecting learning and memory, processing speed, and executive function. Impact on quality of life and daily function can be profound. Little is known about health professionals' perceptions of this problem.

Aim: to explore oncology nurses' awareness and knowledge of cancer-related cognitive impairment (CRCI).

Methods: Semi-structured interviews were conducted with oncology nurses working in Australian hospitals. Seventeen nurses were interviewed, including 4 purposively sampled breast cancer nurses. Transcribed interviews were analysed based on interpretative phenomenological analysis.

Results:

Participants were female, median age 50 years (29 - 61). Most (88%) worked in acute hospitals and 53% saw patients during active treatment.

Six themes were identified: i) role of nurses, ii)'knowing the person', iii) tension in acute healthcare system, iv) incorporating evidence, v) awareness and knowledge of CRCI, and vi) patient care. Participants described using patient-centred approaches to care and education; e.g., tailoring information to need, and offering reassurance and empathy when CRCI was raised. Nurse observations of CRCI were consistent with prior research: participants felt CRCI was real and common, but expressed uncertainty about its cause, duration, impact, and management. Participants indicated they lacked skills to assess CRCI. Despite patient reporting CRCI as a major problem, nurses perceived it as low impact. This, together with their uncertainty about assessment, management and their limited time, impacted discussion about CRCI with patients, reducing the quality of education offered to patients. Challenges within the healthcare system were acknowledged to impact delivery of care and patient education, particularly late effects. Need for training and resources in CRCI was emphasised.

Conclusions: Oncology nurses reported awareness of CRCI but limited understanding and knowledge of assessment or management. Nurses would benefit from training about CRCI and evidence-based management recommendations.

Abs # 25

I just need a referral

Daniel Byrne¹

1. Chandlers Hill Surgery, Happy Valley, SA, Australia

In this short talk I want to discuss the role of the GP in Cancer Survivorship.

As a generalisation the GP is often left out of the "cancer journey" as the patient is busy with treatment that is usually hospital focused. Often the only contact a patient will have with their GP is to organise referrals for specialists or maybe complete paperwork for Centrelink or income insurance. Occasionally we help with access to psychology services via Mental Health Care Plan Once the patient transitions into the "survivor" stage the role of the GP can take on a much more significant role. The issues of ongoing physical health, monitoring, future screening, reviews, mental health and psychosocial issues all need to be considered.

- Issues to consider:
 - · What was the level of the relationship between the GP and the patient like before diagnosis?
 - · What is the level of interest of the GP in Cancer Survivorship?
 - · Does the patient see a role for the GP?
 - · Has there been a good handover from the treating team to the GP?
 - Have concepts of Share Care and use of information technology been maximised?

GPs now have access to Medicare funded item numbers that can help support a structured, planned, team based approach to future care.

In an ideal scenario the GP (with the help of a practice nurse) can arrange a Management Plan, Team Care Arrangements including up to five Allied Health visits per year (such as exercise physiology, physiotherapy, OT, podiatry etc), Home Medication Reviews and Psychology services.

I will describe the "ideal" level of care that could happen if every service and item number available was accessed and compare that with what tends to happen in reality in busy General Practices combined with time poor patients wanting to get on with their lives post cancer.

Empowering survivors to achieve their own goals of care: The role of self-management

Afaf Girgis

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Australia has some of the highest cancer survival rates in the world. Despite improvements in survival rates and prognosis, a cancer diagnosis remains a major life stressor and treatment is often invasive, placing significant psychological, physical, social and existential demands on the person diagnosed and their carers. Between appointments, most patients and carers manage these demands on their own. Importantly, evidence suggests that active coping strategies, such as information-seeking, lead to more positive outcomes than avoidance strategies such as denial. However, patients are often dissatisfied with the information they obtain from health professionals and find other information resources overwhelming. The concern is that information dissatisfaction negatively impacts on quality of life and without appropriate knowledge, patients and carers often revert to trial and error in self-care.

The challenge of supporting the growing population of cancer survivors to achieve optimal health and well-being has led to considerations of various models of survivorship care, including self-management. As a core member of the care team, a cancer survivor can play a central role in achieving their own goals of care, supported by a jointly developed care plan and collected of patient reported outcomes (PROs) to identify any ongoing or new issues of concern. This presentation will provide an overview of the current state of research into self-management and describe the PROMPT-Care project, which includes the development of an e-health platform which will deliver evidence based, tailored self-management information which is responsive to the types and levels of problems and needs reported by survivors through periodically collected PROs, hence enabling them to take an active role in decision making and managing their ongoing care and recovery.

Abs # 27

Shared care of cancer patients in primary and specialist care - proposal for a principle based implementation process.

<u>Bogda Koczwara</u>¹, Jon Emery ², Patsy Yates³, Bruce Mann⁴, Julia Fallon-Ferguson⁵, Danielle Mazza⁶, Geoff Mitchell⁷, Ian Williams⁸, Kate White⁹

- 1. Flinders Centre for Innovation in Cancer, Bedford Park, SA, Australia
- 2. The University of Melbourne, Carlton, Vic, Australia
- 3. Queensland University of Technology , Brisbane, Qld
- 4. The Royal Melbourne and Royal Womens Hospital, Parkville, Vic
- 5. The Primary Care Collaborative Cancer Clinical Trials Group, Nedlands, WA, Australia
- 6. Monash University, Notting Hill, Vic
- 7. The University of Queensland, Ipswich, Qld
- 8. Camp Hill Medical Centre, Brisbane, Qld
- 9. University of Sydney , Camperdown, NSW

Background: While contributing to multidisciplinary care (and sharing in care) could be considered a generic skill for all health professionals, shared care is not just a skill – it is a distinct and well defined process. Shared care offers a number of advantages to patients - treatment closer to home and greater engagement of their primary care provider in care and more comprehensive and holistic approach to care. Evidence supports non-inferiority of shared care in a number of cancer settings and potential for cost savings. Despite its potential, shared care is infrequently taken up, possibly due to challenges related to its implementation. We have undertaken a review of evidence and stakeholder consultation to develop recommendation regarding driving principles for successful shared care and the resulting implementation process.

Methods: A rapid review of systematic reviews and RCTs relevant to shared care was undertaken. This was followed by a face to face meeting with practitioners involved in shared care delivery followed by a draft development and wider stakeholder consultation.

Results. Based on current best evidence and stakeholder consultation a set of principles was developed that were specific to shared care and necessary for its successful delivery. The principles included acceptability to all parties involved (ie providers and patient), flexibility re scope, design and process, clear expectations, communication pathways, implementation process cognisant of resources needed, integration and evaluation. Based on the principles outlines a proposed implementation pathway and supporting resources will be presented.

Conclusion: Shared care is a proven option for delivery of cancer care which is associated with improved patient outcomes. Its successful uptake is dependent on key principles that will inform a successful implementation process.

The ProCare Trial: an RCT of shared care for follow-up of men with prostate cancer

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- 1. University of Melbourne, Carlton, VIC, Australia
- 2. Department of Medical Oncology, Peter MacCallum Cancer Centre, Melbourne, VIC, Australia
- 3. School of Psychology, The University of Sydney, Sydney, NSW, Australia
- 4. Urology Department, Fremantle Hospital, Perth, WA, Australia
- 5. School of Public Health, The University of Sydney, Sydney, NSW, Australia
- 6. Genesis Cancer Care, Royal Perth Hospital, Perth, WA, Australia
- 7. Department of Cancer Experiences Research, Peter MacCallum Cancer Centre, Melbourne, VIC, Australia

Introduction

Men with prostate cancer require long term follow-up to monitor disease progression and manage common adverse consequences of treatment. There is growing recognition of the potential role of primary care in cancer follow-up. No previous trials have tested a model of shared care for prostate cancer.

Methods

The intervention was a shared care model of follow-up visits in the first 12 months after completing treatment for prostate cancer with the following components: a survivorship care plan, GP management guidelines, register and recall systems, screening for distress and unmet needs and patient information resources. Eligible men had completed surgery and/or radiotherapy for low-moderate risk prostate cancer within the previous eight weeks and had a GP who consented to participate. Men were randomised to the intervention or current hospital follow-up care. Study outcome measures collected at baseline, 3, 6 and 12 months included anxiety, depression, unmet needs, prostate cancer-specific quality of life (PCSQoL) and satisfaction with care. Clinical processes and health care resource usage were measured.

Results

Eighty-eight men were randomised (56% of eligible men approached), 45 to shared care; 85 were followed-up at 12 months. 91% of GPs agreed to participate. There were no differences between groups in anxiety, depression or PCSQoL at any time point, although scores of distress were low throughout. The two recurrences which occurred in the shared care arm were referred to specialist care within 1 week. At completion men in the shared care arm were significantly more likely than those receiving usual care to choose shared or primary care led care as their preferred model of follow-up (74% vs 41%). Health economic analyses are in progress.

Conclusions

Shared care of prostate cancer is feasible and shows no sign of significant harms. Following direct experience men prefer this model of care to usual care.

Abs # 30

Supporting Cancer Survivors in Victoria: What have we learnt?

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A key Victorian cancer reform is a commitment to improving the way hospitals help people who have survived cancer transition to life after their initial treatment. In 2011-2014, the Department funded six pilot projects to explicitly trial models of 'survivorship' care. These projects provided support to those recovering from melanoma, breast, blood, bowel and mixed cancer types. One pilot focused on adolescent and young adult survivors.

Project aims included:

- Improving our understanding of the needs of specific survivor groups, what models of care and resources work best for them and how can existing health care resources be harnessed
- Promoting partnerships and improved coordination of cancer survivorship care between hospital-based services, primary care and cancer-related non-government organisations
- Providing survivors with information/resources about what to expect after treatment, how to manage any side effects of their treatments and healthy behaviours to improve well-being.

By following the evolution of these projects, their learning experiences and their outcomes over a three year period we have identified some of the key program design elements to inform the next phase of policy and service development in survivorship care in Victoria. We have also obtained insights into system change including, the role of partnerships and collaborative approaches.

A transferable model of survivorship care

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Introduction

The Barwon South West Survivorship Project was funded to develop a model of care transferable across tumour streams and regional and rural centres.

To extend the window of opportunity provided by nurse led intervention, and in recognition that treatment effects may arise years later, the project framework was to include primary care and community health to ensure long term holistic follow up.

Objectives

Individual nurse led consultations and survivorship care plans were utilised to raise health literacy and empower participants in their recovery and health outcomes. General Practitioners (GPs) were engaged as essential partners in surveillance and to prepare for timely shared care or discharge arrangements.

Method

Participants attended 2 individual nurse consultations focused on health assessment, goal setting, provision of a treatment summary, specific tumour related information and allied health and community referrals.

GPs and practice nurses were consulted to identify communication requirements and to correlate with primary practice processes and GP Chronic Disease Management Plans. Transition to allied health and community services was also achieved by aligning with the language, frameworks and services of rehabilitation, chronic health care and health prevention.

Results

The survivorship service achieved significant results in health literacy, was highly rated by project participants (N=99) in meeting survivorship issues, and by GPs, allied health providers and cancer specialists across three sites. Key approaches and tips for developing a transferable model across tumour streams and sites will be presented

Conclusion

This project developed a service model with processes and strategies that were successfully transferred across three sites and nine tumour streams while engaging cancer, primary care and community services to ensure people completing cancer treatment receive long term health care opportunities.

Abs # 32

Provision of survivorship care for patients with haematological malignancy at completion of treatment: a national cancer nursing practice survey

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Abstract

Background: The haematological cancer survivor population is increasing. Many survivors report long-term post-treatment physiological and psychosocial effects. Cancer nurses' reports of their role, confidence levels, practices and barriers in relation to the provision of survivorship care for patients with haematological malignancies are examined in this study.

Methods: A total of approximately 1300 cancer nurses caring for patients with haematological malignancies were invited to participate in a survey. The survey was distributed to all cancer nurses at a Queensland tertiary cancer care centre and via email through two national professional bodies for cancer nurses in Australia.

Results: In total, 423 cancer nurses (33%) completed the survey. Overall, the majority of participants agreed that all survivorship interventions included in the survey should be within their nursing role. Nurses were least confident in discussing fertility, employment and financial issues with patients and discussing information about identifying signs of cancer recurrence. The least frequently performed interventions included discussing fertility, intimacy and sexuality issues and communicating survivorship care with the patient's primary care providers. The most significant barriers perceived by participants were lack of dedicated end-of-treatment consultation, time, an appropriate physical location, and educational resources; and survivorship care not being a priority for the organisation.

Conclusion: Nurses report they have a key role in survivorship care. A model of survivorship care that addresses the barriers identified in this survey has the potential to improve survivorship care provision. More dedicated training opportunities are required to enable nurses to deliver quality survivorship care and improve outcomes for patients with haematological malignancies.

Just the tip of the iceberg: Evaluating the impact of a nurse-led survivorship service on the health literacy of cancer survivors.

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- 3. Deakin University, Burwood, Melbourne
- 4. Barwon South Western Regional Integrated Cancer Service Consumer Advisory Board, Geelong, VIC

Introduction: Health literacy, ie the ability to seek, understand and use health information, is essential for cancer survivors if they are to effectively manage their own long-term health needs. Lower levels of health literacy have been shown to impact negatively on health outcomes. The Barwon South Western Survivorship service was established to support survivors to develop knowledge and understanding for the sequelae of their cancer treatment, available support services and resources and the importance of adopting healthy lifestyle behaviours long term.

Objectives/Aims: To design, implement and evaluate a unique and innovative model of survivorship cancer care with adaptability for application to rural and regional Victoria.

Description/Methodology: Cancer survivors within two years of completing curative treatment from nine tumour streams received the nurse-led service. A survivorship plan was developed with the patient during two consultations with the survivorship nurse. The survivorship nurse communicated with the participant's GP and gained sign-off of the survivorship care plan from the lead cancer specialist. The Health Literacy Questionnaire (HLQ) was completed by the participants at three time points - prior to the survivorship intervention, one week and three months post intervention. Baseline demographic information was collected.

Results: The sample of 99 participants had an average age of 59 years (range 21-84 years) and comprised more female participants (56%). A significant change in the mean scores was observed in healthcare provider support (p=0.025); having sufficient information (p =0.002); critical appraisal (p = 0.001), and navigating the healthcare system (p=0.04); improvement in actively engaging with healthcare providers, approached significance (p=0.09).

Conclusions: This project has led to the design and implementation of a survivorship service that has proved advantageous to participants. The provision of information using a systematic approach demonstrated improved health literacy levels, which may influence survivors' long-term health outcomes following completion of cancer treatment.

Abs # 34

Developing a Cancer Survivorship Monitoring System for South Australia

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Background - Currently in South Australia there is no mechanism for collecting patient reported outcomes (PROs) experienced by cancer survivors (ie. quality of life and unmet needs). PROs are not routinely collected in clinical settings and are not part of the Clinical Cancer Registry data set due to the difficulty of collecting this information. With a predicted increase in cancer prevalence across the state the need to monitor psychosocial impact of cancer is paramount to evaluate the care needs of cancer survivors. Data related to PROs are a key gap in population level data to inform cancer control activities.

Aim - The aim of the project is to establish the feasibility of collecting PROs and developing a minimum dataset and model for cancer survivorship monitoring for South Australia.

Strategy - Cancer Council SA is leading an engagement strategy with key stakeholders to establish the requirements to set-up and implement a cancer survivorship registry, undertake research to test the feasibility of collecting PROs from cancer survivors and linking this data to clinical and population registry data, and if possible advocate and seek funding to establish broader implementation.

Program - Stage 1 - undertake a systematic review to identify existing cancer survivorship registries and in particular best practice. Stage 2 - develop a minimum dataset and monitoring survey. Stage 3 - Conduct a pilot study at FCIC to determine the feasibility of collecting PROs post cancer treatment and monitored over time from cancer survivors with curative intent. Stage 4 - scope opportunities to progress and develop the infrastructure for a state-wide population based model.

Implications -Monitoring cancer survivorship will enable a better understanding of the psychosocial needs of cancer survivors to inform consumers, health service delivery, policy makers, researchers and advocacy. It will address a critical gap in cancer control data.

Using digital technology to empower and support people affected by cancer and health professionals.

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Background and context:

The ability to provide access to information and support as needed, regardless of location and time, is vital for people affected by cancer¹, confirming the need to provide interventions, information, and support via the internet.² This also provides a convenient gateway to services and support for the continued cancer care of cancer survivors.³ Following these findings, Cancer Council NSW (CCNSW) piloted a series of online webinars, to address some of the workplace and personal issues affecting people affected by cancer.

Aim:

To deliver accessible, life stage appropriate information and support to people affected by cancer and health professionals, regardless of location and time constraints.

Strategy / tactics:

- To deliver cost effective webinars
- Identify research evidence of the unmet needs of people affected by cancer
- Collaborate with health and business professionals regarding webinar topics
- Collaborate with people affected by cancer regarding their personal experience
- Webinars are recorded and available for viewing at any time after the event.

Programme / Policy process:

CCNSW works with an online conferencing provider who manages and delivers the webinars as well as a social media agency that promote and recruit for webinar participants. CCNSW invites panellists, with relevant expertise to participate live, along with someone who has been affected by cancer to provide a lived experience.

Outcomes / What was learned:

Digital technology is an effective way to deliver information to a wide audience. At the time of writing, we have conducted six (6) webinars and received in excess of 1544 registrations. Health professionals made up 25% of the registrations; results anticipated from of effective collaboration and promotion with cancer treatment centres and allied health professionals. An exit survey reported that on average 98% of the people who watched the webinar live would register for future webinars and refer others to attend.

Abs # 36

"Exergaming and Lymphoedema Management": The use of Nintendo's Wii Fit™ yoga program in the management of breast cancer-related lymphoedema.

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This project investigates a new form of exercise that can be used in the management of lymphoedema in post breast cancer patients through the use of the Nintendo Wii Fit gaming program. The study aims to determine whether the Wii Fit yoga program is both safe and effective in the management of breast cancer-related lymphoedema (i.e. shows a reduction in arm extracellular fluid volume after exercise). Participants underwent a yoga program on the Wii Fit, which had been tailored for patients with lymphoedema according to current literature. The exercise program ran for 16-36 minutes. The participants underwent measurements bioimpedence spectroscopy (to measure total arm fluid levels) prior to commencing the exercise, as well as immediately post exercise. Preliminary results from a control group of non-lymphoedema participants (n = 10) showed a mean reduction in arm fluid of 45mL in both arms, which equates to 2.36 % loss. As well as this, results on a post breast cancer lymphoedema patient (n = 1) showed a total volume loss of 130mL. The affected (lymphoedema) arm showed similar loss to the unaffected arm (60 mL and 70 mL respectively), which mirrors the results of the normal patient group. The study aims to be completed on more lymphoedema paticipants (total aims to be approx. 10 participants) to further explore the aim. Anticipated results for more lymphoedema participants will show a decrease in fluid levels as well as a high degree of patient enjoyment and ease using the program. It is expected that this exploratory study will influence other to study this area, and that a new form of lymphoedema management will be uncovered.

Development and Usability of Rekindle, a web-based psychosexual resource for all cancer survivors and their partners

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Introduction: Cancer survivors have identified sexuality as a significant survivorship concern. Unfortunately, amongst providers and researchers the impact of changes to sexuality continue to be underestimated, leaving survivors and their partners with inadequate access to support. This study describes the development and usability testing of a personalized, easily-accessible, cost-efficient and sustainable web-based resource, called *Rekindle* integrated within the Cancer Council NSW supportive care services.

Methods: The *Rekindle* design and content was based on: i) empirical evidence gathered from a literature review; ii) an online survey of psychosexual support intervention preferences; iii) qualitative interviews with cancer survivors and partners; iv) consultation with multi-disciplinary stakeholders; and v) usability testing.

Results: Data from 324 cancer survivors demonstrated a clear preference for online delivery (32%) and interest in participating in interventions with their partner (32%). Embarrassment (28%) and lack of privacy (22%) were the most commonly cited barriers to uptake of psychosexual support. Interviews with 32 survivors (18 male) and 8 partners (4 female) highlighted the importance of communication and the need for self-guided communication skills training. The barriers and facilitators to effective sexual communication were explored with changes to relationship perception, masculinity and self-confidence identified as three intervening phenomena. Rekindle proved user-friendly and usability testing results informed final development.

Conclusions: Rekindle addresses sexual concerns by providing empirically-validated strategies in a private, personalized and user-friendly resource. Rekindle has been designed to include up to seven topics including: psycho-education, cognitive restructuring, communication skills training, medical and non-medical strategies to address sexual concerns, sensate focus and mindfulness. Rekindle users will be prescribed topics according to their reported sexual concerns. Barriers and facilitators to development will be discussed as well as recruitment strategies. The Rekindle clinical trial is in its initial stages of recruitment and results aim to inform the future implementation of psychosexual support.

Abs # 38

Delay in diagnosis of lung cancer in general practice

Sahban Wael Al Shehabi

Introduction:

lung cancer is the second most common cancer disease among men and the third most common cancer disease among women.

GPs act as gatekeepers, distinguishing patients who can be investigated and treated in primary care from patients who need specialist care. Considering the high prevalence of symptoms of lung cancer in general practice and its low incidence it is neither possible nor desirable to avoid all diagnostic delay in lung cancer in primary health care.

Presenting symptoms of lung cancer in general practice

The patients presented with many different symptoms. Cough was the most common complaint, followed by dyspnoea, fatigue, fever, and weight loss the number of symptoms increased over time between the first presentation and the referral leading to the diagnosis

Cause Delay in general practice:

the time from the patient's presentation of the first symptoms or signs that could be related to the lung cancer until referral to hospital.

Delay in general practice was subdivided into:

- 1-doctor delay: time elapsed without investigation of cancer-related symptoms and signs.
- 2-Waiting times The median system delay was 14 days and it was mainly due to waiting times for chest X-rays,
- 3- Chest X-ray with no suspicion of cancer
- 4-comorbidity caused misinterpretation chest x-ray and blood test .

5- Lack of follow up appointments

conclusion

If we want to reduce diagnostic delay in lung cancer in primary care, one possibility is to reduce waiting times for chest X-rays and other investigations ordered in primary care. Another possibility is to motivate GPs to undertake an earlier reassessment of the diagnosis for the two thirds of patients who are not diagnosed upon their first consultation. This will require that GPs become aware of the low sensitivity of chest X-ray

Collaborating to deliver an effective survivorship program

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Background:

Research indicates survivors have an increased risk of weight gain, functional impairment, fatigue, other chronic diseases, secondary cancers, and premature mortality. Responding to this, Cancer Council NSW (CCNSW) runs an Exercise and Nutrition Routine Improving Cancer Health (ENRICH) program for people who have finished active treatment and their carers. ENRICH is a 6 week face-to-face program led by professionals comprising physical activities and healthy eating information, aiming to transition survivors to a healthy lifestyle. Recently, CCNSW has partnered with the Sydney Survivorship Centre (SSC), whose aim is to provide a holistic approach to survivorship care.

Aim:

The aim of the collaboration was to implement regular ENRICH programs that are mutually beneficial to both organisations and provide opportunities to triage people into other programs.

Strategy:

Discussions between the two organisations originated because:

- The SSC needs entry level programs for cancer survivors.
- The SSC has limited resources available to develop programs
- ENRICH has undergone a comprehensive evaluation and is replicable
- CCNSW needs a model of delivery for ENRICH that is sustainable and cost-effective.
- CCNSW and SCC identified a mutual benefit to collaborating on ENRICH

Program process:

SSC health care professionals deliver the program. They generate ongoing referrals from their survivorship clinic and promote the program to other oncology clinicians. Attendance at ENRICH is now a prerequisite for some survivorship programs.

CCNSW assesses potential attendees for their suitability and eligibility, provides program resources and compiles evaluations. These processes enable survivors to be directed into other suitable CCNSW programs and ongoing program improvements to be made.

Outcomes:

- N = 75 attendees
- Majority of these have attended other SCC and CCNSW survivorship programs

Implications:

Through this collaborative approach, additional pathways to programs have been realised, improving the quality of care available to cancer survivors.

Abs # 40

Beyond Breast Cancer Survivorship Day

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Adaptation to life beyond the consequences of cancer and its treatment is a high priority amongst consumers and the health care system. Transition to survivorship, however, is often problematic due lack of a consensus model of care. There is also an increasing focus on supported self-management for people affected by cancer at this time of transition. In response to these factors a collaboration between two McGrath Breast Care Nurses, Support4Cancer which is a local cancer peer support foundation, the Grampians office of Breastscreen Victoria and Grampians Integrated Cancer Service organised the inaugural Beyond Breast Cancer forum in Ballarat in March 2014.

Well recognised presenters from local and Melbourne based services presented sessions designed around contemporary survivorship themes including; nutrition and exercise; management of lymphedema; emotional issues; sexuality and intimacy; fatigue; and complementary therapies. Numerous trade displays reflecting the content were also offered.

Forum content was further validated by the release of a Breast Cancer Network Australia member survey which listed the 5 top challenges for breast cancer survivors which were ongoing wellbeing, emotional health, managing side effects, impact on family and friends, and financial pressure.

Fifty two women living in the Grampians region of Victoria attended. Written feedback indicated that 69% of the attendees completed participant evaluation forms. Two satisfaction ratings of the day were "very good" (64-89%) or "good "(6-31%).

Success of the forum has demonstrated the value of multiagency collaboration to deliver tailored low-cost forums or programs to benefit survivors. The collaborative will use both participant evaluations and team reflection to develop further initiatives. Two successful funding applications are in planning and delivery phases.

Recommendations from the collaborative include utilising diverse skills and knowledge, including consumer experience, to improve access to relevant information, knowledge and skills while using consumer evaluation and feedback to maintain relevance of content.

Abs # 41

Fertility Follow-up After Cancer Treatment

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Fertility is a significant and emotive issue for many people faced with a diagnosis of cancer and many of the treatments for cancer, eg. surgery, chemotherapy or radiotherapy, may have detrimental effects on the fertility of the patient after cancer treatment. Ideally fertility preservation treatment options should be offered to people before cancer treatment. We know these options are offered or utilised to varying degrees depending on the individual's circumstances and the nature of their cancer and treatment.

The need for timely fertility follow-up, assessment and support *after* cancer treatment is recommended whether or not prior fertility preservation techniques have been carried out, but there has been little research regarding what comprises appropriate fertility follow-up.

The aim of this project was to review current literature to provide a general framework for fertility follow-up in the setting of cancer survivorship. To achieve this we set out to answer the following questions:

- 1) How long after cessation of cancer treatment is fertility follow-up most useful?
- 2) How are the effects of cancer treatment on fertility assessed, with specific focus on assessment of ovarian reserve and endometrial damage for females and sperm quality for males?
- 3) What options are available to cancer survivors of all ages to preserve or assist their chances of conceiving whether or not they have previously undertaken fertility preservation techniques prior to cancer treatment?

Recommendations regarding optimal long-term fertility follow-up after cancer treatment will be presented. These recommendations are relevant for all health professionals providing support in the cancer and fertility fields as well as any person, partner or family member of someone who has faced a diagnosis of cancer who has an interest in their future fertility.

Abs # 42

On a path to personal post traumatic growth: From cancer patient to social media lobbyist

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Introduction: I was 26 years old and already 2 years down the cancer path when my Lebanese background threatened to discriminate my search to find a stem cell match and my final hope to cure my cancer.

81% of donors on the Australian Bone Marrow Donor Registry are of North Caucasian background and the remainder are split across tiny percentages of various ethnic backgrounds. Sadly many groups have less than 1% representation (1). The lack of presence of minority ethnic groups on the worldwide bone marrow registry affects the lives of many people within Australia who are unable to find a stem cell match as a result of their heritage.

Now as a survivor of cancer I have established "Ur the Cure" which uses multiple forms of social media to achieve the aim that no person has to feel the same despair. As I grappled with the survivorship period, I used this time to work on my project and found it helped in my recovery.

Aim: My mission is to improve human leukocyte antigen diversity on stem cell registries nationally and worldwide.

Conclusions: During my own facebook and media campaign, which aimed to search for my lifesaving transplant match, I realised the power of social media as I gained access to people within Australia and all over the world. I even met the president of Lebanon and together we discussed the non-existent registry there. Inspired by these amazing events and calling upon my marketing qualification, I embarked on a social media public awareness campaign to address the inequalities of "health" discrimination I had experienced.

My journey to date has been filled with observations and learnings as I work towards my goal of building awareness within the general public about representation of ethnic groups on the national bone marrow registry.

 GN Samuel, IH Kerridge, M Vowels, A Trickett, J Chapman, T Dobbins 2007, "Ethnicity, equity and public benefit: a critical evaluation of public umbilical cord blood banking in Australia", Bone Marrow Transplantation, 40, pp. 732-733

Developing a Survivorship Culture at the Mater Cancer Care Centre: Showcase of Projects

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The Mater Cancer Care Centre (MCCC) prides itself in providing holistic care to patients across the cancer trajectory. Despite having a well-established model of care that involves a multidisciplinary approach, the focus remains in the active treatment phase. There is strong evidence that survivors experience a significant and multitude of unmet needs post treatment. Therefore, attention to this population is essential to ensure that timely and effective services are offered. Research indicates that medical, nursing, and allied health clinicians all have an important role in providing survivors with relevant information, education, enhanced coordination of care, with effective communication channels between providers.

Only a few national cancer centres have established successful survivorship care programs. In the past two years, the MCCC has created a culture that has increased the awareness of survivorship in patients and clinicians. The model of care is a patient-centred care model. Projects generated have had a heavy consumer engagement focus. A survey on patients' preferences for long term "survivorship" follow up was conducted over a 12 month period. Factsheets were developed with extensive input from patients. The mindfulness-based stress reduction survivorship program has had lots of positive feedback and a group therapist manual for a couples group has been developed and the first pilot group is aim to begin in 2015.

It expected that the resources, surveys, and audits that have been developed and underway will provide the MCCC with a direction and purpose that will be of benefit to the community. Having a survivorship clinic will facilitate cancer patients' transition into the survivorship phase, without the fear of a lack of support.

Abs # 44

'Engage' Community Forums to raise awareness of Gastro-Intestinal cancers – an initiative led by GI Cancer survivors and carers.

GI Cancer Institute/Australasian Gastro-Intestinal Trials Group (GICI/AGITG) Consumer Advisory Panel (CAP)¹

1. GI Cancer Institute/Australasian Gastro-Intestinal Trials Group (GICI/AGITG), Sydney, NSW Introduction:

GI Cancer survivor and carer members of the GICI/AGITG CAP have been the drivers of a series of Forums to raise community awareness about gastro-intestinal cancers, treatments, clinical trials, support services and survivorship.

Method:

Community forums were held in Sydney, Melbourne, Adelaide and Brisbane in 2013-2014. The program included expert clinician speakers on the topics of GI Cancer - the Big Picture, Latest Advancements in Research and Treatments, Quality of Life Research together with a GICI/AGITG CAP member presenting their 'survivorship' experience story. Ample time for questions was followed by an opportunity for further engagement as participants partook of refreshments and expo-style displays by organisations such as Colostomy Association, Cancer Council, Look Good Feel Better to name a few.

GICI/AGITG CAP members guided the development of the program, selection of speakers and relevant local contacts, groups and organisations. GICI/AGITG staff provided the support necessary to implement the Forums.

Results:

487 people attended in total, and highly positive feedback was obtained.

This encouraged the GICI/AGITG CAP to propose holding forums in rural and regional areas. Following a successful funding application the Engage project is now a Cancer Australia *Supporting people with cancer* Grant initiative, funded by the Australian Government, enabling a series of regional forums during 2015-16, commencing in Central Qld in March 2015. Engage Forums will also be held during November 2014 in Western Sydney, Perth, and Canberra.

Conclusions:

Engage Community Forums are an initiative established by survivors and carers to raise awareness of gastro-intestinal cancers and encourage participation in clinical trials. This collaboration between survivors, carers, GICI/AGITG, cancer clinicians and local communities is a novel model that may help address regional inequalities in cancer outcomes, improve screening numbers and increase clinical trial participation.

Abs # 45

LiveWell. A description of a pilot goal setting workshop for cancer survivors at the Olivia Newton-John Cancer and Wellness Centre.

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Live Well Program

The Live Well Program is the initial pilot phase of an intended, three phase Survivorship Plan proposed by the Wellness and Supportive Care team at the Olivia Newton-John Cancer and Wellness Centre. This abstract provides a synopsis of phase one of the program - The Live Well Program.

Participants were invited to attend a four week workshop aimed at facilitating engagement in their own health and wellbeing after completion of treatment. The workshop's aim was to enhance participant's confidence in their ability to make and maintain changes to achieve improved wellbeing outcomes. It is anticipated that participants will complete a personal health and wellbeing plan over the course of the workshop that focuses on their own goals for developing and maintaining a healthy lifestyle including physical activity and healthy eating and addressing psycho-social issues such as anxiety and fear of recurrence. Key workshop components would include self-management strategies such as goal setting; action planning; problem solving; self-monitoring; stress management; information provision; sharing experiences and positive feedback.

Target Population

- · Adult patients who have completed treatment for cancer in the previous 3-6 months
- · Participants for this pilot will primarily be drawn from the Haematology and Breast Clinics.
- · Their family members, friends and caregivers who may wish to come along with the person who has been treated for cancer.

Self Management Framework

The framework proposed for the Live Well Program is based on that of chronic disease self-management programs (CDSMPs) which have been well documented as a successful method of enabling patients to engage in supported self-management.

Evaluation Activities

HeiQ —a pre and post evaluation tool will be used to evaluate outcomes for participants. In addition a post implementation surveymonkey survey will be used.

Abs # 46

Breast cancer shared care follow-up from demonstration project to sustainable model

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Aim

To develop a sustainable model of shared care for breast cancer patients at Monash Health by:

- creating a shared care standard pathway
- initiating shared care from diagnosis
- improving communication between the specialist team, patient and GP
- employing GP support for patients close to home
- fostering patients transition towards wellness
- prioritising acute service resources towards patients with greatest need

Background

In 2013, 4075 Victorians were newly diagnosed with breast cancer. The five year relative survival rate for those with stage 1 and 2 cancers is 100% and 94% respectively which has resulted in increased numbers of health service follow-up visits placing pressure on limited acute sector resources. Research indicates that shared care for breast cancer follow up is a safe and effective alternative. Initiative

Monash Health initiated a shared care pathway for breast oncology patients, informed by previous work undertaken in the 2010-11 Cancer Australia shared care demonstration project and supported by additional funding from Cancer Australia.

Patients enter the pathway at their post-surgical review and are encouraged to see their GP at the following intervals:

- post diagnosis
- post Multidisciplinary Team Meeting and treatment planning
- during active treatment as needed
- at end of active treatment
- the 6 month point between Monash Health annual reviews
- annually after 5 years when the majority of care is provided by the GP.

Monash Health gives patients and GPs a shared care follow up plan at the first annual review and patient education is carried out by breast care nurses. Patients are not discharged, and can rapidly access the health service as needed. A nurse led wellness clinic is planned to assist patients with un-met supportive care needs and to encourage a positive approach towards their health. In addition a GP active learning module is under development. To date there are 312 patients on the pathway.

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Advances in Oocyte Cryopreservation: Egg Freezing is now a viable fertility preservation option for oncology patients.

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- 2. Flinders Fertility, Flinders Medical Centre, Bedford Park, SA, Australia
- 3. Fertility SA, Adelaide, SA, Australia
- 4. Repromed, Dulwich, SA, Australia

Cancer therapy poses a threat to female fertility. The gold standard for fertility preservation has been controlled ovarian hyperstimulation (COH) to collect eggs (oocytes) followed by *in vitro* fertilisation of the eggs to produce embryos which could be cryopreserved. This approach was problematic for single women who did not want to use donor sperm, or for women who did not wish to produce embryos. It was also not advised for women whose need for cancer treatment was so urgent that the 2-6 week delay required to collect oocytes put them at risk.

Freezing unfertilised oocytes is now a viable option due to recent advances in cryobiology. Previously, a process of slow freezing was used with 100-150 frozen oocytes required to result in a pregnancy. The recent introduction of vitrification whereby oocytes are frozen rapidly in a small volume of cryoprotectant produces far better success rates with only 4-5 frozen oocytes required for a pregnancy.

Success rates vary depending on the patient (age and other factors) and Assisted Reproduction Technology (ART) provider, but in Adelaide rates are in the following ranges; ~95% of oocytes survive vitrification and thawing, ~80% of oocytes undergo fertilisation and ~100% of the fertilised oocytes undergo normal embryo development *in vitro*. In one ART centre recently, 3 patients had embryos transferred and these resulted in 3 pregnancies.

Advances in oocyte cryopreservation are being combined with new COH regimes whereby oocytes can be collected after only 8.5 days. Oocyte freezing and shorter COH regimes are not suitable for all patients, and are contraindicated in women diagnosed with a hormone responsive cancer. For oncology patients fertility preservation expenses can be billed to Medicare, but not oocyte storage costs. In conclusion, oocyte cryopreservation is now offered routinely to oncology patients and is a viable option for fertility preservation.

Abs # 48

"Life, not cancer" - A pilot of community based survivorship care delivery in Southern Adelaide.

Michael Fitzgerald¹, Melinda Richardson¹, Catherine Hughes¹, Bogda Koczwara¹

1. Flinders Medical Centre, Adelaide, South Australia, Australia

Background

Cancer survivors have poorer long term health than non- cancer survivors. Often their needs are not addressed adequately by health services. Comprehensive approaches to meet the needs of cancer survivors that focus on health, well-being and self-management plans may improve the health of cancer survivors. Engaging health professionals at the primary prevention level is critical in supporting healthy living choices, late effects monitoring and prevention and monitoring of cancer recurrence. Self-management and chronic disease management is a well evidenced platform for managing long term health and health effects of disease or treatment. The objective of this pilot is to develop a model of cancer survivorship care that can be developed and implemented by a variety of health care professionals across multiple health settings.

Method

With support from the Southern Adelaide Health Alliance (SAHA) – an initiative aimed at developing innovative programs and partnerships with providers outside acute health facilities, we have established contact with interested providers in order to examine needs, consider potential models of care and identify or develop resources to support them. The outcome measures will include uptake of survivorship care, acceptability to users and problems and needs addressed.

Results

Senior cancer nurses (specialist nurses) have been identified as pivotal in partnering with to increase capacity for development of survivorship care plans. Four GP practices indicated willingness to be involved. These practices vary in size and infrastructure which will serve as excellent tests for applicability of any proposed model. A critical component identified by GP's is access to timely communication and guidelines that enable clarity of care planning events. They also identified a desire to have a central contact point for clarification of issues. Results of stakeholder consultation and conceptual model development will be available at the time of presentation with final implementation and evaluation planned for the remainder of 2015.

Adult cancer survivors' experience of healthcare interactions and unmet needs in healthcare services: a systematic review Peter Hallett^{1, 2}, Matthew Stephenson ¹

- 1. The Joanna Briggs Institute, The University of Adelaide, Adelaide
- 2. Calvary Rehabilitation Hospital, Walkerville, South Australia

The aim of this presentation is to provide a summary of a qualitative systematic review that synthesised the best available evidence of adult cancer survivors' experiences of their interactions with health care practitioners and the health care system. In addition, the review synthesised the evidence on unmet needs identified by cancer survivors in the provision of services in the health care system. This review considered studies that included adult (18 years and older) survivors of solid tumours, excluding lymphoma, who were under 60 years of age at time of initial diagnosis. A cancer survivor was defined to include people having concluded their primary treatment that may be in remission or cured, but not have active advanced disease/ metastatic disease or be undertaking palliative treatment. This review considered studies that investigated the experiences of cancer survivors, their interactions with the health care system and heath care practitioners, and the unmet needs in health care services they experienced over the course of their survivorship. The health care system included health care practitioners of medical, nursing, allied health and complimentary therapies but excluded alternative therapies. This review considered studies that focused on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research. Qualitative research findings were pooled using the Joanna Briggs Institute Qualitative Assessment and Review Instrument. This involved the aggregation or synthesis of findings to generate a set of statements that represented that aggregation, through assembling the findings rated according to their quality and categorising these findings on the basis of similarity in meaning. These categories were then subjected to a meta-synthesis in order to produce a single comprehensive set of synthesised findings that can be used as a basis for evidence-based practice.

Abs # 50

An overview of the structure of the multi-disciplinary Oncology Rehabilitation Program at Calvary Rehabilitation Hospital and evaluation of the program.

Peter Hallett¹

1. Calvary Rehabilitation Hospital, Walkerville, South Australia

As rising numbers of people are diagnosed with cancer there is an ever increasing pool of cancer survivors – those living with and beyond cancer. As a result, cancer survivorship is now recognised as an important aspect of patient care. Assisting these individuals to remain active, employed and healthy will have a significant impact on patient outcomes and reduce the burden on health care resources. With the increased number of cancer survivors, there is an increased focus on the need for rehabilitation services to improve their functional outcomes. Calvary Rehabilitation Hospital has developed a 6 week outpatient multidisciplinary rehabilitation program consisting of exercise, education and meditation. This presentation will provide an overview of this program, an evaluation of the service to date and reflections for further service development.

Abs # 51

A role for massage in cancer survivorship

Deborah Hart¹, Anne-Marie Halligan¹

1. Oncology Massage Ltd, Woden, ACT

With cancer survivorship increasing there are over 800,000 cancer survivors in Australia who have a higher incidence of progressive and recurrent disease including diabetes, heart disease, further cancers, chronic pain, lymphoedema, neuropathy and organ damage. Cancer patients experience a variety of side effects and treatment outcomes which effect them throughout all stages of survivorship. When considering the stages of survivorship, Acute, Extended and Permanent or Long Term, massage can offer not just symptom relief during the acute and extended phases but benefits in immune support and endocrine function into permanent and long term stage survivorship. Regular massage can reduce stress and lower blood pressure, two factors that have an effect on cardiovascular disease. Massage has been shown to impact many of the common side effects of cancer treatment and suitably trained massage therapists can be a source of education and support for cancer survivors. Research shows that massage reduces symptoms during cancer treatment such as pain, fatigue, nausea, depression and anxiety and increases endocrine and immune function. The aim of this paper is to highlight the benefits of massage therapy for patients during conventional cancer treatment and through all stages of survivorship. Studies demonstrating these benefits are few but small and large studies alike do show positive results and with further research well timed use of massage therapy may bring an innovative approach to using massage in this way. This paper suggests a variety of possible directions for research opportunities into the effects of massage on this population of survivors and the need for continued research in this area.

Survivorship issues for young women – a BCNA Consumer Representative's reflection

Danielle Spence, Desi Heliotis¹, Kathy Wells¹

I. Breast Cancer Network Australia, Camberwell, VIC, Australia

Desi Heliotis is a Consumer Representative and Community Liaison with Breast Cancer Network Australia (BCNA). She also cofacilitates a support group for young women in Adelaide.

Desi was diagnosed with breast cancer at the age of 37. When diagnosed, Desi had a three year old daughter and was undertaking study. Desi had to make difficult and confronting choices about her future, particularly in the area of fertility. She also experienced significant fatigue from chemotherapy and radiotherapy, preventing her from spending precious time with her young daughter.

Following treatment, Desi undertook BCNA's Science and Advocacy Training program to become a BCNA Consumer Representative and represent the needs and experiences of women affected by breast cancer on advisory committees and research projects. She has provided consumer input on a funding application and has been appointed to assist with a project aimed at helping women make decisions about their fertility options.

Recognising the need for greater support for young women in Adelaide in 2007 Desi and several others began a support group for young women. The group meets for breakfast on Sunday mornings, providing an informal and supportive atmosphere for women to discuss issues relating to their diagnosis and treatment, as well as ongoing survivorship issues.

In this presentation, Desi will reflect on her breast cancer diagnosis and subsequent decision to become a Consumer Representative and co-facilitate a focus group. In doing so, she will discuss the ongoing survivorship issues she and the other young women in her support group must manage. These include ongoing fatigue, changes in body image, whether to continue hormone therapy despite difficult side effects, fertility, making decisions about breast reconstruction, and managing ongoing financial expenses. She will also reflect on the continuing information needs of young women in the survivorship period.

Abs # 53

Strengthening survivor's roles in cancer trials advisory groups.

Joint Community Advisory Group (JCAG)^{1, 2}

- 1. Primary Care Collaborative Cancer Clinical Trials Group (PC4), Perth, WA
- 2. Psycho-Oncology Clinical Trials Group (PoCoG), Sydney, NSW

Introduction:

Cancer survivors and carers play a vital role in the 14 national cancer clinical trials groups. This includes our input around the research-study design, outcome measures, the potential of burden, inequity and challenges for trial participants, suggestions for improving recruitment, refining study and information materials and general 'consumer perspectives' of the importance or priority of study directions.

The Joint Community Advisory Group (JCAG) for the Psycho-Oncology (PoCoG) and Primary Care Collaborative Cancer Clinical Trials (PC4) Groups has implemented a peer-support program for sharing ideas and to strengthen the collaboration, capability and confidence of members to operate in this unfamiliar role.

Method:

The JCAG was first established in mid 2010 with 10 members, and the peer-support program was initiated by the PoCoG and PC4 Executive Officers. As JCAG members are scattered across Australia, regular contact between peer-support pairs is generally by email, skype or phone.

Results:

Members of JCAG value and strongly support the formal peer-support process.

Unique to JCAG is our broad non-tumour-type-specific remit, trials that are complex interventions and not testing cancer drugs, and the primary care perspective including cancer prevention, early detection and screening. Hence JCAG members feel we benefit from sharing the diversity of experiences as cancer survivors, carers and/or community members interested in clinical trials to improve cancer care and quality-of-life outcomes.

We feel the quality of feedback, in our advisory roles, is enhanced by this collaborative approach. Feedback from researchers indicates they greatly appreciate the JCAG input, and increasingly involve us at the early 'concept development' stage of studies.

Conclusions:

Participation in clinical trial advisory groups is a steep learning curve for most new-comers. Supporting cancer survivors to share their experience and contribute most effectively in this research environment is a means to improving the quality and focus of cancer clinical trials.

Supporting Return to Employment after Cancer in Disadvantaged Communities

Amy Marshall¹, Vikki Knott², Monique Bareham³, Paul Ward¹, Jon Emery ⁴, Julia Fallon-Ferguson⁵, Ian Olver⁶, <u>Bogda Koczwara</u>⁷

- 1. Flinders University of South Australia, Adelaide, Australia
- 2. Menzies School of Health Research , Adelaide, SA, Australia
- 3. Cancer Voices SA, Adelaide, SA, Australia
- 4. University of Melbourne, Carlton, Vic, Australia
- 5. The Primary Care Collaborative Cancer Clinical Trials Group, Nedlands, WA, Australia
- 6. The Cancer Council of Australia, Sydney, NSW, Australia
- 7. Flinders Centre for Innovation in Cancer, Bedford Park, SA, Australia

Background: Maintenance of employment has substantial benefits to an individual in enhancing a sense of personal worth and identity as well as providing financial security. Despite these benefits, cancer survivors have difficulties returning to work, are at greater risk of unemployment after cancer and the risk increases with lower socioeconomic status. Currently there are limited resources available to cancer survivors to assist them in returning to employment after cancer treatment.

This project aims to improve return to work of cancer survivors by developing a suite of resources that support return to work (RTW) with a particular emphasis on disadvantaged communities, and to disseminate these resources widely via Cancer Council Australia's existing Wiki-platform and other relevant networks.

Methods: The project will conduct a number of focus groups purposefully sampled from rural and outer metropolitan areas with a high prevalence of socioeconomic disadvantage and evidence of poorer cancer outcome. We will invite cancer survivors, their carers and health care providers from diverse disciplines, along with experts on employment/RTW to discuss barriers to RTW as well as gaps in preferences for intervention and support with regard to RTW. We will then convene an Expert Consensus Group who will determine the content and format of the resources, informed by the results of the focus groups and information from extant RTW literature and an audit of available RTW resources.

Outcomes: This project will result in the development of a suite of RTW resources comprised of key evidence-based recommendations, practical resources and tools presented as a series of digital modules accessed via Cancer Council Australia's existing wiki-platform. Modules will be tailored to address the diverse cancer-related RTW needs identified for disadvantaged consumer groups, with resources provided for consumers, oncology professionals, general practitioners and employers.

Abs # 55

Coping-Together: A Self-Management Intervention to Address the Psychosocial Needs of Couples Affected by Cancer.

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- 1. University of New South Wales/Ingham Institute, LIVERPOOL BC, NSW, Australia
- 2. University of New South Wales/Ingham Institute , LIVERPOOL, NSW, Australia
- 3. McGill University, Montreal, Canada
- 4. University of Newcastle, Newcastle
- 5. University of Queensland , Brisbane
- 6. University of Louisville, Louisville
- 7. Deakin University, Burwood, Victoria

Background: Patients and partners report similar reactions to a cancer diagnosis, including fear, anxiety and distress, with a sizable minority reporting sustained reactions for extended time periods. Such reactions may negatively impact on the wellbeing of both members of the dyad with findings indicating that patient and partner reactions mutually influence how the other person adapts. Aims: a) To identify core concerns, information provision, information satisfaction, distress, appraisal (illness and caregiving), dyadic adjustment and coping in couples adjusting to a cancer diagnosis; and b) to develop a self-management intervention to address gaps in supportive care approaches for couples.

Results: Patients and partners identified their main concerns as psychosocial rather than medical in nature. Compared to patients, partners reported receiving significantly less information on psychosocial matters, e.g. support services (p = .03) and self-care (p = .03); and were less satisfied with information received (p = 0.007), potentially because it didn't address their core concerns and was not targeted specifically to partners.

To address such issues we developed Coping-Together, a novel self-management coping skills intervention targeting couples. Its primary focus is on the development of practical coping behaviours, Coping-Together addresses current gaps in supportive care resources, focusing on psychosocial issues such as the impact of diagnosis on the couple's relationship and dealing with emotional reactions. Initial pilot testing (n=42 couples) demonstrated a trend (defined as p <0.3) towards improvements in patient distress and illness appraisal, lowered partner stress, caregiver burden and financial strain, and improved illness appraisal and sustained dyadic

Conclusions: Coping-Together potentially addresses the psychosocial needs of couples dealing with cancer in a way that is feasible, acceptable and sustainable due to its self-directed nature. There is opportunity for Coping-Together to support vulnerable couples, particularly those living in rural areas or with limited access to supportive care services.

The JumpStart Blood Cancer Survivorship Program- Bridging the gap between dependence and renewed independence in everyday life

Tennille Lewin¹, Andrew Smith¹

1. Leukaemia Foundation, Preston, VIC, Australia

Aim

Re-engaging in everyday life after blood cancer treatment can be filled with challenges including complex fatigue, lack of energy and decreased cardiovascular fitness. The JumpStart program was designed to empower people to re-engage in their everyday lives using principles of self-health management.

Methods

Participants in Victoria and Tasmania (n=18) responded to expressions of interest advertised at the Leukaemia Foundation. Participants were 18+ years of age, in remission and had written medical clearance from their GP. Those having active treatment or unstable disease were excluded.

Participants outlined their everyday goals using the Canadian Occupational Performance Measure (COPM) and received individualised and tailored intervention from a supportive care provider, occupational therapist, exercise physiologist and clinical dietician over a 4 month period which informed the community based individualised self-health-management programs. Quantitative data collected included physiological measurements (VO2 Max, BMI) COPM performance and satisfaction surveys.

Results

Results included clinically significant increases in COPM Performance scores of 3.28 and COPM Satisfaction scores of 4.02. Physiological changes included an average increase of 12% in VO2 max, no significant change in BMI and weight. Our quantitative data appears to support our aim of using Self Health Management Approach in overcoming complex blood cancer fatigue allowing participants to increase performance and satisfaction in their everyday lives.

Conclusion

Programs that address the needs of the increasing blood cancer survivorship population need to be client-centred, sustainable and individually tailored. The JumpStart Program outcomes were achieved by using the existing roles of the Leukaemia Foundation support services coordinators and linking blood cancer survivors in to the appropriate community based health professionals and Medicare primary care schemes, which are currently available to the blood cancer population across Australia.

Abs # 57

Defining the role of occupational therapy in cancer survivorship

Nicole Buckland¹, Lynette Mackenzie¹

1. University of Sydney, Lidcombe, NSW, Australia

Background / Aim: Increasing rates of cancer survival in Australia indicate that more people are living with long-term side effects of the disease and its treatment, and survivorship is now often considered a distinct phase of cancer care. Whilst occupational therapists play an integral role in multidisciplinary care for many chronic illnesses, and have a recognized role in palliative care oncology, there is little evidence documenting the profession's role in cancer survivorship. This study aimed to explore the views of Australian occupational therapists regarding current and best practice for people with cancer, from diagnosis through to survivorship.

Methods: A cross-sectional online survey was developed and distributed through the national Occupational Therapy Australia database to collect responses from occupational therapists in diverse areas of practice around Australia.

Results: A total of 204 completed surveys were returned. More than 85% of respondents worked with people with cancer at least occasionally and 33% of practice occurred in community settings. Participants perceived equipment provision to be the most common intervention (94%), followed by energy conservation (90%) and pressure care (78%). Lack of funding for occupational therapy positions and a lack of recognition of the role of occupational therapy by health professionals and consumers were seen as key barriers to best practice.

Conclusion: This study highlights the need for occupational therapists to commit to research efforts and to work collaboratively with the multidisciplinary team to develop long-term routine treatment pathways that address the needs of cancer survivors. Recognition of the value of occupational therapy involvement in providing interventions to assist cancer survivors in the community is needed to extend services that are currently available, and education programs are needed to enable occupational therapists to develop their services.

Abs # 58

Evaluating subtle cognitive changes in women following chemotherapy treatment for breast cancer: A functional perspective.

Lynette Mackenzie¹, Judy Ranka¹, Christine Chapparo¹

1. University of Sydney, Lidcombe, NSW, Australia

Cognitive changes following cancer treatment are controversial. There are several opinions about the cause of these changes, especially in women following treatment for breast cancer. Regardless, a high proportion of women report subtle cognitive

changes. These include difficulties with attention, concentration, memory, language, prioritising and problem solving, as well as agitation, anxiety and an impaired ability to cope with stressful situations. These difficulties are reported to impact negatively on aspects of daily life such as organizing a household, returning to work, driving, and managing pin numbers and accounts.

Currently, there is no functional assessment available that has been validated for use with this population. Neuropsychological assessments document cognitive impairment but do not assess how cognitive impairment impacts directly on functional tasks in everyday life. One test, the Perceive, Recall, Plan and Perform System (PRPP) appears suitable. It assesses how well client-specific everyday tasks are carried out and the cognitive strategy application abilities and difficulties impacting on performance. Errors in task performance identified include inaccuracies, omissions and repetitions of steps. Cognitive strategy application difficulty impacting on performance is assessed on 38 observable behaviours that represent the domains of attention and perception, memory and recall, planning and problem solving and carrying out actions. Preliminary analysis of qualitative data provided by Australian women recovering from breast cancer using the PRPP assessment framework supports further investigation of its use. Once a valid and reliable functional assessment is identified, interventions to address the cognitive changes impacting on daily life can be developed and evaluated.

The aim of this paper is to describe the PRPP assessment and to compare the difficulties reported by women following breast cancer with the strategy application behaviours assessed on the PRPP. A case study will be used to illustrate key findings obtained from the PRPP and how these may guide intervention.

Abs # 59

Why aren't we 'Measuring what matters to cancer survivors' in Australia?

Julie Marker¹, Agnes Vitry^{1, 2}

- 1. Cancer Voices South Australia, Kensington Park, SA, Australia
- 2. Quality Use of Medicines and Pharmacy Research Centre, University of South Australia, Adelaide, SA

Issue:

Despite around one million cancer survivors alive in Australia today, very little is known about our 'survivorship' experience and what happens in the interval between cancer diagnosis and death.

In Australia, survivor advocates highlight mismatches between the:

- priorities and concerns of post-treatment survivors versus the narrow clinical focus of the healthcare system; and also
- limited data collected, collated and analysed to monitor survivors' care and outcomes in Australia, versus the level of survivorship analysis undertaken in other countries such as USA and UK.

We need data assessing health, wellbeing, long-term impacts, outcomes; costs, quality, equity and effectiveness of care as well as informing services accountability and planning.

For example, when, where, who experiences:

- long-term cancer or treatment impacts: physical (eg pain, fatigue, impotence, incontinence, lymphoedema,), emotional (eg anxiety, relationship breakdown, disfigurement) practical (eg financial, work);
- cancer recurrences;
- the need or impact of rehabilitation or support services;
- the presence and/or development of comorbidities;
- outcome disparities (eg vulnerable groups by age, race/ethnicity, socioeconomic status).

Background:

Data from the USA and UK show that 25-30% of cancer survivors are in poor health or disabled, unable to return to work or have limitations in cognitive, mental and physical functioning and psychological distress (1,2,3); What is the situation in Australia?

"With the number of cancer survivors expected to increase by more than 30 percent in the next decade, medical and public health professionals must be diligent in their efforts to help reduce the burden of cancer on survivors and their families."(1)

Recommendations:

Consumers, clinicians, researchers, policymakers and health-economists need to work together to determine succinct and meaningful measures for monitoring cancer survivors in Australia, and ensure this enables international comparisons of survivorship outcomes.

A national inquiry is needed to review and assess the major concerns of cancer survivors.

- 1 Ekwueme DU et al. Medical Costs and Productivity Losses of Cancer Survivors. Oncology Times Oct 2014 http://journals.lww.com/oncology
 - times/Fulltext/2014/10100/Cancer_Related_News_from_the_CDC__Medical_Costs.26.aspx
- 2 Macmillan Cancer Support UK. Throwing light on the consequences of cancer and its treatment. 2013 http://www.macmillan.org.uk/Documents/AboutUs/Research/Researchandevaluationreports/Throwinglightontheconsequencesofcanceranditstreatment.pdf

 3 MacMillan Cancer Support UK. Routes from Diagnosis 2014 http://www.macmillan.org.uk/Documents/AboutUs/Research/Researchandevaluationreports/Routes-from-diagnosis-report.pdf

Abs # 60

Work in progress: A regional systems approach to development of an end of treatment summary for patients and their GPs from cancer specialists

Lea Marshall¹

1. Grampians Integrated Cancer Service, Ballarat, Victoria

Shared care between specialist oncology services and primary care as an accepted model of cancer care in Victoria is a work in progress. Many consequences of cancer and its treatment are able to be effectively managed in primary care. For those affected by cancer, the strength of primary care is in the sectors in-depth knowledge of chronic disease management and referral to community based care. Transition to survivorship may be facilitated by a survivorship care plan, especially as a means of improving education and communication for and between patients and their GPs. However, barriers such as length of completion time and who should complete the plan remain problematic and unresolved. Grampians Integrated Cancer Service (GICS) is seeking to promote service integration through the enhancement of communication between GPs and specialists across the region. GICS is one of nine Victorian Integrated Cancer Services established to drive best practice and improve outcomes for those affected by cancer. One GICS commissioned report exposed variable consistency of the quality of communication between cancer specialists and GPs and highlighted this as an area for improvement. Two GICS governance groups, the GP Reference Group and the Lead Clinicians Tumour Group, are designing three communication guides at critical points during cancer treatment. These are 'At diagnosis', 'During active treatment' and 'At the end of treatment' to create a whole-of-region approach to consistency of quality communication. The first two guides are now in pilot phase. Development of an end of treatment summary (EoTS) is proceeding carefully. Guidance from peak bodies such as the Australian Cancer Survivorship Centre (ACSC) is raising survivorship issues with the two GICS groups. Awareness from ACSC of existing tools such as the ASCO Treatment Summary and Survivorship Care Plan is also useful. The final EoTS will be decided upon in 2015.

Abs # 61

Survivorship challenges for Australian women with breast cancer

Danielle Spence, Michelle Marven¹, Maxine Morand¹

1. Breast Cancer Network Australia, Camberwell, VIC, Australia

The purpose of this research was to identify the needs and challenges, including survivorship issues, facing Australian women with breast cancer.

A mixed methods survey was sent to 8,157 women with a breast cancer diagnosis, with a 16% response rate. Cross tabulation analysis was performed by age, geographical location, diagnosis and time since diagnosis.

39% (512) of respondents had been diagnosed between two to five years ago; 26% (348) six or more years ago.

86% of respondents had been diagnosed with early breast cancer, 14% were living with secondary breast cancer. 54% were from a major city, 45% from regional, rural or remote areas. 87% of respondents were 45-74 years.

Women were asked to rate a range of challenges that had affected them since their diagnosis. The top five challenges were ongoing wellbeing 59% (n=780); emotional health 56% (n=749); managing side effects 52% (n=686); impact on family and friends 45% (n=593); financial pressure 41% (n=541).

59% of women diagnosed more than two years ago were concerned about their ongoing wellbeing. Younger women (under 55 years) were more concerned about their wellbeing (74%) and emotional health (68%) compared to those over 55 years (57% and 55%).

Qualitative responses (n=351) highlighted information needs for women, with a strong focus on survivorship issues such as physical activity and healthy eating, sexual wellbeing and information for employers when returning to work. Managing hormone treatment side effects was also consistently raised by women.

Input was sought from respondents on specific issues they would like BCNA to advocate on their behalf (n=641). The most significant advocacy issue was the financial cost to women of treatment 37% (n=240).

Survivorship issues remain key challenges for Australian women, in particular the ongoing psychosocial needs of Australian women and the financial impact of breast cancer.

What women say - experiences from participating in a survivorship project

Fiona McRae¹, Lee Kennedy¹, Robin Curwen-Walker

1. BREACAN, MELBOURNE, VIC, Australia

Introduction: The Victorian Government funded a number of survivorship projects in 2012/13. One of these was a partnership project designed to investigate a model of care that improved quality of life for women completing definitive treatment for early breast cancer. In total, 184 women participated in this project. Evaluation revealed strong consumer acceptance of the project and important opportunities for secondary prevention.

Objectives/Aims:

This presentation will outline results of project evaluation pertaining to experiences of women who participated. It will also highlight opportunities for increased uptake of health and well-being messages based on the strong rapport developed between women and their treating team as they undergo diagnosis and treatment.

Description/Methodology Acceptability, effectiveness and impact of the process and its elements, including a Nurse-led Clinic (NLC), were evaluated with a follow up survey of 107 participants (65% returned). Twenty telephone interviews with participants were then undertaken to capture qualitative information about the process, outcomes and impact, and to identify areas for improvement. Women were asked about their experience of attending the NLC, including practical and lifestyle considerations, views on the care plan, and possible improvements to the appointment process.

Results:

From the project several features emerged including how women understood the term 'lifestyle' and how this related to their lives not just while experiencing cancer. Other features include the importance of continuity of care and how women rated the NCL. Overall outcomes were positive and 39% reported having made lifestyle changes as a result of attending NLC.

Conclusions:

While evaluation showed a high level of acceptance of the NLC, women identified multiple barriers to achieving lifestyle change and utilising the follow up care plan. Opportunities exist to enhance positive lifestyle change through the use of evidence based interventions such as Motivational Interviewing – using women's own experiences to make lifestyle changes.

Abs # 63

What matters to me? Consumer engagement to inform a survivorship model of care in the ACT

<u>David Larkin</u>^{2,3,1}, Megan Nutt², Toni Ashmore², Desmond Yip², Angela Rezo², Marian Currie^{3,1}

- 1. Faculty of Health, Disciplines of Nursing and Midwifery, University of Canberra, Canberra, ACT, Australia
- 2. Cancer Ambulatory and Community Health Support, ACT Health, Canberra, ACT, Australia
- 3. ACT Health Research Centre for Nursing and Midwifery Practice, ACT Health, Canberra, ACT, Australia

The Canberra Region Cancer Centre (CRCC), which commenced operation in 2014, is now the primary adult tertiary referral hub for cancer diagnosis and treatment in the ACT and South East New South Wales region, servicing a population in excess of 500,000 people. A significant part of the vision to provide this population with integrated and contextually appropriate cancer care will involve implementing a Cancer Survivorship Model of Care for the ACT Health Directorate's Cancer Services.

Phase 1 of this Project aims to engage and consult with local consumers and service providers to help inform priorities in establishing this model of care. For this purpose, the researchers have devised survey tools based on current issues in cancer survivorship research. These tools have been widely distributed in both paper and electronic format to consumers (people who have had a diagnosis of cancer and carers) and clinicians. Selection criteria have been identified to reflect the unique population groups serviced by the CRCC.

Specific objectives of Phase 1 of this Project are to define the term cancer survivorship within the local context; to inquire about the physical, emotional and practical support needs of cancer consumers; and to examine coordination of resources and support from a clinician perspective.

Data collection is ongoing until the end of 2014. Preliminary results indicate our cohort define survivorship as living with cancer from the time of diagnosis, through treatment and beyond. Emerging themes include managing the psychosocial impact, adjusting to altered roles and expectations, and living with an unknown future after treatment, with these needs able to be better met. Findings are showing that information on the disease, treatment and its side effects is more helpful in the early stages of the cancer trajectory, whereas there is a continual need for psychosocial information and support throughout.

Ahs # 64

Hospital-based supported self-management intervention for colorectal cancer survivors: Acceptability and feasibility in New Zealand

Inga O'Brien¹, Diana Sarfati², Louise Signal², Janine Bycroft³

- 1. Univeristy of Otago Wellington, Wellington, New Zealand
- 2. Univeristy of Otago, Wellington, New Zealand
- 3. Health Navigator New Zealand, Auckland, New Zealand

Background: The cancer journey often includes medical management and self-management that is enhanced by appropriate and timely information and support. Supported self-management is routinely employed with people managing chronic illness in primary care settings but its utility as an intervention during hospital-based cancer treatment has not been adequately explored. If shown to be acceptable and feasible in the oncology setting, supported self-management may enable people living with and beyond cancer to better manage physical and psychosocial survivorship transitions.

Methods: The stepped study design included a theory-driven preclinical phase leading to a two stage exploratory trial. *Stage I modeling involved focus groups and key informant interviews. Stage II was a randomised pilot study of The Flinders Program with people who were undergoing active treatment for colorectal cancer in Wellington, New Zealand. Outcomes measured include patient-reported self-management competency, resilience (CD-RISC), quality of life (SF12v2), distress (Distress Thermometer), and patient experience for intervention and control groups pre- and post-assessment.*

Results: Stage I thematic analyses indicated self-management impacts of cancer often go unaddressed. The stage II pilot (n=27) showed that the supported self-management intervention is acceptable in the oncology setting. Eight of 14 people (57%) assigned to the intervention group self-identified at least one of thirteen areas of perceived moderate to low self-management competence (score of 4 or less on the self-report Partners in Health Scale). Of this sub-group, a clinically significant difference in score from 0.2 to 0.9 (p = 0.06) was reported post-intervention.

Conclusions: Supported self-management intervention improved outcomes for some people managing colorectal cancer survivorship. It was especially useful for people with self-reported low confidence in self-management in some areas, particularly those who lived alone with comorbidities. *The intervention was found to be acceptable and feasible for routine application in the oncology clinical setting. Further* clinical trials are warranted.

Abs # 66

Life after the Big C

Don J Piro¹

1. Cancer Clinical Health Network, Nuriootpa, SA, Australia

This presentation is a reflection of my life after the Big C as a stage 4 Bowel Cancer Survivor.

It is now over 10 years ago that I was originally diagnosed with the Big C and it has been quite a rollercoaster ride. All survivors know the rigours of surgery, treatment, side effects, impact psychologically on yourselves, your partners, family and friends. It seems that it never ends.

I think what I want to share most of all is; I chose to "Live with Cancer" and I created opportunities to change my life, move away from the masculine training men can have and look at life differently as many of us do when we have a life threatening disease.

During the early of years of treatment there is shock, fear, anxiety and stress as you progress through the medical system, doctors and appointments that seem to define your days. We can get moments of peace and calm before the next round of tests, scans and settle a bit.

Part of my healing was to focus on "wellness from within", using inner resources, complimentary therapies that helped my spirit grow & I could focus on healing from within.

During that time I also moved, started life afresh, using this time as an opportunity to have new beginnings with my wife and family, work and health. I joined a gym started bike riding, started my own business and then I wanted to give something back, using all of my skills to help others. I became involved as a consumer on various committees in policy, research, and advocacy.

This is my story of Life after Cancer, choosing to live and I would love to share it with you.

Abs # 67

Physical and psychosocial issues after definitive treatment for breast cancer

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- 1. Western Hospital, Footscray, VIC, Australia
- 2. Breast Unit, Royal Womens Hospital, Parkville, Victoria

Background

Many women with a diagnosis of breast cancer will survive and experience a range of physical and psychosocial consequences of diagnosis and treatment.

Method

Flinders Centre for Innovation in Cancer Survivorship Conference 2015

Those with early breast cancer or ductal carcinoma in situ were invited to an hour long breast nurse consultation after their definitive treatment(not including endocrine therapy). In preparation they were asked to complete quality of life surveys (FACT B, menopause rating scale, and distress thermometer). Issues raised were addressed and referrals to support services arranged.

Results

183 of 274 invited patients attended. 96(55%) reported significant distress, often from lack of energy, poor sleep, and inability to work or participate in household activities. Problems with sex life and intimacy were reported in 28/89. 166 referrals were offered, particularly for peer support, menopause clinic and psychology. In a follow up survey completed by 65% participants over a third reported making lifestyle changes, especially regarding exercise and diet, as a result of the breast nurse consultation. In addition most agreed that their GP was an important partner with the hospital in ongoing follow up.

Conclusion

Breast cancer survivors have a significant burden of distress following treatment. The nurse led clinic is an acceptable and effective opportunity to assess unmet needs, provide information. support and referrals to community services.

Abs # 68

Volunteering for Cancer Council NSW; A Survivor's Experience

Alan Pottie¹, Melissa Nixon¹

1. Cancer Council NSW, Wagga Wagga, NSW, Australia

Living in idyllic Wagga Wagga as a 52year old married father of 3, Alan Pottie was living the dream. He was shocked to be diagnosed with tonsil cancer in 2010, but Alan did not let cancer define him. Turning a "lemon into lemonade", Alan turned the negative experiences of his cancer journey into a positive opportunity, learning to master the media, helping his community to achieve early detection practices and empowering other cancer patients to become cancer survivors.

Since diagnosis, Alan has managed to build both personal and professional resilience into his life through many volunteering roles and opportunities with Cancer Council NSW. This presentation outlines Alan's journey with the Cancer Council, from nervous beginnings to local media treasure. Alan describes the many volunteer programs he engages in as well as discusses the multifaceted benefits to be gained by others interested in Volunteering.

Abs # 69

Sharing the care: an innovative model of care for GP and specialist collaboration in the management of late effects of cancer treatment.

Josephine M Samers¹, Natalie Goroncy¹, Mary Dwyer¹, Greg C Wheeler¹

1. Peter MacCallum Cancer Centre, East Melbourne, VICTO, Australia

With improved survival rates and increasing awareness of the potential long term complications of complex cancer treatments, innovative models of care need to be developed to provide evidence based surveillance and ongoing management of long term cancer survivors. Whilst the identification of risks arising from cancer and its management including systemic agents, radiotherapy, surgery or bone marrow transplantation is often highly specialised, the resulting need for screening, chronic disease management, lifestyle modification and psychosocial support is often best managed in primary care by GPs who provide ongoing, coordinated, accessible wholistic care to patients in their local community.

In response to increasing clinic numbers and patients' preference to have their ongoing management outside the hospital setting, the Late Effects Service at Peter MacCallum Cancer Centre has developed a shared care model which aims to provide integrated care between the patient's GP and the multidisciplinary specialist Late Effects team. Through the development of evidence based guidelines, patient stratification and the provision of ongoing information and support for both patients and their GPs, cancer survivors at low to moderate risk of long term complications are able to receive ongoing care close to home with their usual GP supported by the specialist late effects team.

Abs # 70

Harnessing e-mental health to promote resilience in adolescent and young adult cancer survivors.

<u>Ursula M Sansom-Daly</u>^{1, 2, 3}, Claire E Wakefield^{1, 2}, Richard A Bryant⁴, Brittany C McGill^{1, 2}, Eden G Robertson^{1, 2}, Sarah J Ellis^{1, 2}, Emma L Doolan^{1, 2}, Pandora Patterson^{6, 5}, Richard J Cohn^{1, 2}

- 1. Kids Cancer Centre, Sydney Children's Hospital, Randwick, NSW, Australia
- 2. School of Women's and Children's Health, The University of New South Wales, Kensington, NSW, Australia
- 3. Sydney Youth Cancer Service, Prince of Wales/Sydney Children's Hospitals, Randwick, NSW, Australia
- 4. School of Psychology, The University of New South Wales, Kensington, NSW, Australia
- 5. Cancer Nursing Research Unit, Sydney Nursing School, The University of Sydney, Sydney, NSW, Australia
- 6. CanTeen Australia, Sydney, NSW, Australia

Background 'E-health' technologies have significant potential to extend the reach of evidence-based psychological support to vulnerable, isolated populations. For adolescents and young adults (AYAs) with cancer, the time following cancer treatment

completion can be a particular time of psychological vulnerability as they attempt to return to 'normal'. Assisting AYAs to develop adaptive coping skills at this time of transition may prevent later distress. Our team has developed 'ReCaPTure LiFe' (Resilience and Coping skills for young People To Live well Following Cancer), an online intervention for AYAs aged 15-25 years in the first year post-treatment. This national phase II randomised controlled trial (RCT) aimed to establish the feasibility, acceptability, and efficacy of Recapture Life, relative to an online peer-support group control, and a 12-week waitlist.

Methodology Recapture Life is a manualised program that promotes resilience using cognitive behavioural therapy (CBT) techniques tailored to the AYA cancer experience. It involves six, weekly, small-group sessions, delivered online by a psychologist using innovative video-conferencing technology. To date, 31 AYAs have completed the program from across five states in Australia. Groups have been conducted with participants >4000km apart, across different timezones. Early data indicate improved quality of life (p=0.033), and reduced distress (p=0.021), anxiety (p=0.015), and need for help (p=0.024) following the program.

Conclusion Recapture Life is a promising model of support for AYAs across Australia. This talk will discuss new online models of evidence based support for young people living with cancer, examine how CBT can be tailored to the cancer context, and discuss the benefits and ethical/clinical challenges of using online delivery mechanisms for these populations.

- 1. Sansom-Daly UM, Wakefield CE. Distress and adjustment among adolescents and young adults with cancer: An empirical and conceptual review. Transl Pediatr 2013;2(4):167-197.
- 2. Sansom-Daly UM, et al. Online group-based cognitive-behavioural therapy for adolescents and young adults after cancer treatment: A multicenter randomised controlled trial of Recapture Life-AYA. BMC Cancer 2012;12:339.

Abs # 71

Clinical Awareness and Knowledge of Breast Cancer Related Lymphoedema in Australia - An Online Survey

Agnik Sarkar, Richard J Woodman, Changcheng Zhu, Zoe Bogner

As breast cancer survival rates have improved, so too has the occurrence of morbidities associated with its treatment such as Breast Cancer-Related Lymphoedema (BCRL). Research shows that BCRL patients report dissatisfaction with the lack of information provided by their treating clinicians¹.

This study seeks to quantify Australian clinician awareness and knowledge of BCRL regarding its causes, symptoms and management. Demographic and experience data was also collected to identify factors that can influence health professional knowledge.

Oncologists, Breast Surgeons, physiotherapists, Breast Care Nurses, Occuptational Therapists and Massage therapists in clinical contact with BCRL patients were asked to complete a 5-minute web-survey. The survey focuses on basic knowledge of lymphoedema and genetics in the aetiology of BCRL. A knowledge score was then calculated based on the responses. Survey web-links were disseminated via email through representative health organisations

183 (84.7%) of 216 survey responses were complete. Clinicians working in oncology and breast surgery secured, on average, 43.1% and 52.8% of available points respectively. All other groups scored higher. Physiotherapists achieved a mean of 70.6%. On multivariate analysis, occupation has a positive relationship with knowledge score (p=0.00). Each unit increase in the number of professional development events attended was found to improve knowledge score by 2.4% (p=0.00). Similarly, unit increases in self-rated literature awareness of BCRL predisposition elevated scores by 2.5% (p=0.00).

Findings suggest that patient dissatisfaction with their care can be partially attributed to sub-optimal knowledge of BCRL. Investing in professional development, increasing patient contact and improving awareness of literature are potential strategies of strengthening clinician knowledge.

These results can assist in development of educational strategies to augment knowledge of BCRL. Low awareness of developing BCRL can delay or impair the provision of the best possible care to patients, indicating that a sustained focus on clinician education is of vital importance to positive patient outcomes.

Abs # 72

Working together to ensure structured exercise is safe and more accessible for cancer survivors

Jason Schild¹, Tricia LaBella^{2, 1}, Julie Marker²

- 1. Diploma of Fitness, TAFE SA, Regency Park, SA, Australia
- 2. Cancer Voices South Australia, Kensington Park, SA, Australia

Introduction: Despite growing evidence of the benefits of exercise after cancer, uptake and maintenance of physical activity by cancer survivors is limited. The major aim of this scoping study was to commence communication and collaboration between a range of cancer and fitness stakeholders in order to begin exploring ways we could work together to ensure exercise was safe and more accessible for cancer survivors.

Method: A Forum was hosted by Cancer Voices SA and the Diploma of Fitness at TAFE SA in 2014. Almost50 participants, including survivors, exercise physiology and personal training professionals attended. Three speakers gave presentations and these were followed by a discussion among stakeholders to identify issues related to exercise, its safety and utilisation.

Results: A range of issues potentially impacting on the uptake of exercise by cancer survivors were identified. Theses included the risks exercise can have for some cancer clients/patients; what is currently being offered in the way of exercise instruction/support for cancer clients. Inter-professional boundaries, a lack of understanding of fitness trainers' skills, training and expertise, and interest in information about cancer survivorship issues were additional issues identified. Key 'Next steps' elicited during the Forum included recommendations to establish a 'multi-disciplinary working group'; develop a risk screening/stratification tool to assist fitness professionals design appropriate exercise interventions for patients and survivors; clarify and improve understanding of the different skills and qualifications of different professionals; creating a pathway from clinical supported programs to community based programs, through the development of a register of practitioners and services; and, hold further forums for sharing information.

Conclusion: Through working together with cancer survivors and key stakeholders with interest in promoting the benefits of exercise, we aim to further develop methods and approaches to support the implementation of safe and accessible exercise for cancer survivors.

Abs # 73

Fit to Thrive: A Specialised Exercise Program to support patients with a haematological malignancy.

Maryanne Skarparis¹

1. Leukaemia Foundation of Queensland, Dutton Park, QLD, Australia

Research is increasingly showing that physical activity for cancer patients before, during, and post-treatment can improve muscular endurance, decrease symptoms of fatigue, improve balance and flexibility, increase muscle mass, and improve quality of life. A collaborative approach between the Leukaemia Foundation of Queensland and Aspire Fitness and Rehabilitation led to the development of this exercise program, aimed at supporting the growing evidence of the benefits of physical activity for people living with a blood cancer. Fit to Thrive is a free specialised exercise program to support patients from diagnosis, through treatment and beyond. This program aims to assist patients both individually and in a group setting. This allows them to meet their individual goals, enhances their quality of life, and provides them with the best practice in patient care. It also provides valuable data for research into the benefits of exercise for this patient group. The initial intake of the program recruited a total of 30 participants (5 groups of 6 participants). The participants ranged in age from 18 – 75years old and had been diagnosed with a haematological malignancy. Participants were assessed against their own individual responses and improvements. Clinically relevant subjective and objective measures were recorded to assess the program's merits. Fit to Thrive has been a powerfully positive experience for the first cohort of participants. Based on the accumulated data and anecdotal feedback, the program has been able to deliver an individualised approach to rehabilitation in a group setting with dramatic impacts on functional strength, endurance, reducing fatigue and improved psycho-social measures. Every patient improved on every quantitative measure of the study. While the data is yet to be statistically analysed, it does appear to deliver as a pilot program, in showing positive trends.

Abs # 74

What do Australian Oncologists think about cognition and cancer?

Kate Smidt¹, Lynette Mackenzie², Haryana Dhillon³

- 1. Discipline of Occupational Therapy, University of Sydney, Sydney
- 2. Discipline of Occupational Therapy, University of Sydney, Sydney
- 3. Survivorship Research Group, University of Sydney, Sydney

Introduction: With survivorship increasingly recognised as a distinct phase of cancer care, uncertainty has emerged within the oncology community regarding the roles and responsibilities of those caring for cancer survivors. Consequently, many cancer survivors are ill-informed of the potential challenges associated with the survivorship phase. Cognitive changes experienced by cancer survivors have received growing attention as a survivorship issue. Though often subtle in nature, cancer related cognitive changes (CRCC) can have a profound impact on a cancer survivor's quality of life. Nonetheless, cancer survivors' report receiving limited information by treating oncologists regarding this phenomenon.

Objective: We explored oncologists' understandings of CRCC experienced by cancer survivors. This exploration aimed to illuminate on the perceptions of oncology specialists regarding CRCC and how their views influence patient care.

Methods: Fourteen medical oncologists and four radiation oncologists currently practising in Australia participated in this study. Data collection involved individual, semi-structured interviews via telephone. Data were audio-recorded, transcribed verbatim and analysed using a thematic approach.

Results: Four key themes emerged: (1) Beliefs about the impact of priming on cancer survivors' perceived cognitive function (2) Uncertainty of how to best manage CRCC (3) Perceptions of who is more likely to raise concerns regarding CRCC (4) Oncology specialists' perceived role in the management of cancer survivor's cognitive concerns.

Conclusion: CRCC and its impact on the cancer survivor's journey has been under-addressed by oncology specialists and they are uncertain as to potential management strategies. With cancer survival rates increasing, there is a need for specific interventions and management guidelines addressing CRCC and their effects on cancer survivors. Future exploration should focus on the survivor as central to their care, and holistic approaches to CRCC management involving all members of the multidisciplinary health team.

Body weight, physical activity levels, and dietary changes in cancer survivors attending Sydney Survivorship Clinic

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- 2. University of Sydney, Sydney, NSW, Australia
- 3. Concord Cancer Centre, Concord
- 4. Sydney Medical School, The University of Sydney, Sydney

Background: There is growing evidence to suggest obesity and sedentary lifestyle increase the risk of a second cancer diagnosis and cancer recurrence among cancer survivors. Many gain weight due to adjuvant treatment, as a result of cancer and supportive care medications, coupled with lower physical activity (PA) levels. Our aim was to investigate cancer survivor's PA levels, and weight and dietary changes after anti-cancer treatment.

Method: Prospective data collection of adult patients who had attended Sydney Survivorship Clinic from September 2013-September 2014. These patients had localised cancer (breast, colorectal and haematological) and had completed primary treatments (surgery, chemotherapy and/or radiotherapy). At first survivorship clinic visit patients were seen by a multi-disciplinary team including: oncologist/haematologist, cancer nurse, dietitian, psychologist, and exercise physiologist. Baseline demographics, weight history and physical activity levels were assessed via questionnaires and medical record audit.

Results:100 new patients attended the clinic, 78% were female with median age 54 (range 23-80) years, and tumour groups represented: breast 51%, colorectal 35%, haematological 14%). Mean body mass index (BMI) at diagnosis was 27.1kg/m² (range 15.8–53.6kg/m²), and 28.1kg/m² (range 17.6 – 59.1kg/m²) at time of clinic attendance, with 61% classified overweight or obese. 76% gained weight between diagnosis and survivorship clinic attendance (mean 2.9 kg, range: -10.3-24.65 kg). 42% reported meeting physical activity guidelines. Mean time spent doing PA of at least moderate intensity was 49min/week (range 0-330min). Mean sitting time was 357min/day (range 90-960min). 61% self-reported dietary change since their cancer diagnosis (n=46). Conclusion: More than half the patients were overweight before starting treatment and three quarters gained weight during treatment. The majority of patients are not meeting recommended guidelines for moderate intensity PA and spend an average of 6 hours/day sitting. The Survivorship Clinic has implemented a number of lifestyle interventions to address these lifestyle concerns for cancer survivors.

Abs # 76

The experiences and preferences of shared decision making and their associated factors among cancer patients undergoing radiation therapy

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- 2. Department of radiology, Nagoya City University Graduate School of Medical Sciences, Nagoya, JAPAN
- 3. Department of radiation Oncology and Image-Applied Therapy, Kyoto University Graduate School of Medicine , Kyoto, JAPAN
- 4. Department of Breast Surgery, Kyoto University Graduate school of medicine, Kyoto, JAPAN
- 5. Division of Palliative Care and Psycho-oncology, Nagoya City University Hospital, Nagoya, Aichi, Japan

Aim:

Researches suggest that shared decision making (SDM) increases patients' involvement in healthcare decisions but the experiences and preferences of SDM and their associated factors in cancer patients are undetermined. This study aimed to investigate 1) the experiences and preferences of SDM and their associated factors, 2) the factors that associated with the participants who preferred and experienced SDM, among cancer patients undergoing radiation therapy.

Methods:

Cancer patients aged 20 years or older were consecutively sampled when they started radiation therapy at two university hospitals. The patients were asked to complete self-administered questionnaires concerning their experiences and preferences of SDM, psychological distress, physical symptoms, quality of life, sociodemographic and medical factors, physician's communication style (e.g.; "The doctors at the hospital gave me all of the treatment I could have."), and provision of psychological, physical and practical support.

Results:

Among the 260 patients (response rate: 66%), 70% experienced and 85% preferred SDM. 88% recognized their aim of radiation therapy as curative. A multiple regression analysis revealed that one item of physician's communication style ("The staff at the hospital showed respect for me") was significantly associated with experience of SDM and that higher education was significantly associated with preference of SDM.

As for the factors associated with participants who preferred and experienced SDM, univariate analysis revealed 5 items of physician's communication style including treatment information and psychological support was significantly associated. But we couldn't find significant association in multiple regression analysis.

Conclusions:

Communication including respect to patients might increase SDM and physicians need to take patients' education into account when they decide treatment. In addition, communication with enough treatment information and psychological support might enhance the possibility that patients who prefer SDM can get it.

Abs # 78

Research on cancer survivorship in Australia: current status, gaps and needs

Agnes Vitry¹, Julie Marker²

- 1. University of South Australia, Adelaide, SA, Australia
- 2. Cancer Voices SA, Adelaide, Australia

This presentation will review the current status, gaps and needs for research on cancer survivorship in Australia using both a researcher's and survivor's perspective.

Cancer survivors are heterogeneous with regards to their survivorship care needs. Research addressing cancer survivors' long-term medical, psychosocial, and practical needs across the survivorship trajectory is needed.

In 2009-2011, only 9 % of funded research focused on cancer control, survivorship and outcomes research. While there are already national epidemiological statistics on cancer prevalence and incidence, there is still inadequate knowledge on long-term cancer survivorship which is mainly based on patchy, one-off surveys. Research on late adverse effects of treatment of adult cancer survivors is sparse. Research on current cancer care practices and associated health outcomes is restricted by existing barriers to linkage of routinely collected data such as prescribing data. There is also limited research on the development and evaluation of interventions to improve health and quality of life and of cancer survivors.

Research on cancer survivorship is essential to inform the development of a national strategy for achieving high quality cancer survivorship care. The international literature around cancer survivorship is useful but we have limited detailed data from within our own health system. Progress is being made through the development of data linkage facilities and best-practice guide to data access. Cancer survivors do support efforts to ensure that publicly funded datasets can be used effectively and securely to address gaps of current research. Cancer survivors also recommend that more research should be done to better understand the needs of cancer survivors and how to best address the long-term challenges in their health care.

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Sponsors & Exhibitors

Breast Cancer Network Australia

Table #5

Breast Cancer Network Australia (BCNA) is the peak national organisation for Australians personally affected by breast cancer, and consists of a network of more than 100,000 individual members and over 300 Member Groups. BCNA supports, informs, represents and connects people affected by breast cancer. BCNA works to ensure that they receive the very best support, information, treatment and care appropriate to their individual needs.

www.bcna.org.au

Equicare Health Table #3

Equicare Health is the industry's leading provider of oncology care coordination software that improves clinical outcomes for patients, and enables care providers to operate more effectively. Our solution, EQUICARE CS^{TM} , includes functionality for patient navigation, survivorship follow-up and patient engagement. Equicare delivers services using interfaces with Hospital information systems to assist centers in managing large patient populations with minimal administrative overhead. Equicare is a web-based solution used by over 65,000 patients around the world.

www.equicarehealth.com

Fleurieu Cancer Network Table #2

A non funded community based initiative run by dedicated volunteers all touched by cancer, the Fleurieu Cancer Network has:

- 1. Established multi-sectorial partnerships within community, business, government and non government agencies using a top down, bottom up approach for advocacy and support.
- 2. Influenced the design of the Flinders Centre for Innovation in Cancer
- 3. Produced 'My Diary' practical resource for patients
- 4. Produced DVD 'My Cancer Journey- from despair to inspiration' and developed written stories
- 5. Established a generic cancer support group
- 6. Convened three stakeholder 'Working Together' Forums
- 7. Held a Bowel Cancer Awareness event
- 8. Hosted a research focus group for survivors "The Cancer Survivor's Voice"
- 9. Developed and maintained a Website, E-newsletter and Facebook pages

Fleurieu Cancer Network continues to work with both agencies and community assisting to provide a vehicle for the voice of survivors, their family and friends.

www.fcn.org.au

Leukaemia Foundation Table #1

The Leukaemia Foundation is Australia's peak body for blood cancer, funding research and providing free services to support people with leukaemia, lymphoma, myeloma, MDS, MPN and related blood disorders, and their families. Our services, delivered by a national team of around 50 support service staff who are qualified in nursing and allied health, include emotional support, information, education, accommodation, transport, practical assistance and advocacy.

www.leukaemia.org.au

The Australian Cancer Survivorship Centre (ACSC)

Table #6

The Australian Cancer Survivorship Centre (ACSC) was established with funding from The Pratt Foundation, Department of Health Victoria and Peter MacCallum Cancer Centre. Our vision is to optimise the health and wellbeing of cancer survivors and their carers. We focus primarily on the post-treatment phase to maximise our impact.

www.petermac.org/cancersurvivorship

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www.flinders.edu.au/mnhs/mnhs_home.cfm

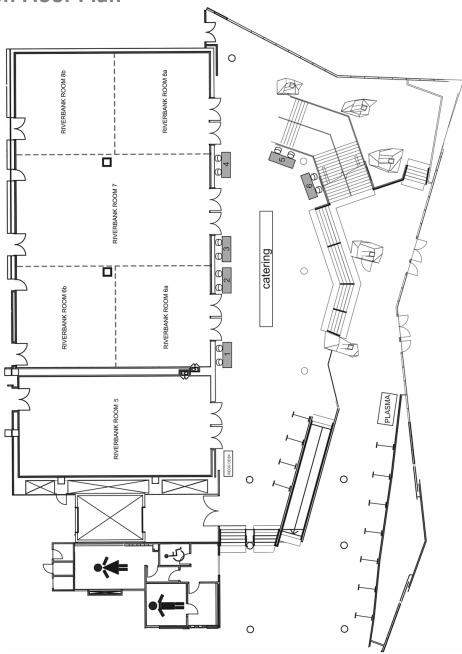
Trulife Breast Care Table #4

Trulife is a world-leading Breast Care company, available worldwide in over eighty countries. With over fifty years of experience in developing innovative Breast Forms, Pocketed Bras and Accessories, to fulfil the needs of today's modern woman post breast surgery. Trulife Breast Care for Every Woman Everyday.

Trulife Breast Care is exclusively distributed in Australia and New Zealand by OPC Health Pty Ltd

www.opchealth.com.au

Exhibition Floor Plan



Notes		

Notes			